

Past, Present and Future: An Examination of Quality of Life in New Zealand and the interRAI Quality of Life Survey

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Dedication

To my wife Stephanie Marie Brandt, Ph.D., our son Lucas Christopher, and daughter Sophia Stephanie. With all of my love.

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Abstract

InterRAI is an internationally validated assessment tool used in many different contexts to assist different groups of people and patients to live fuller, safer and more productive lives. In 2008, the New Zealand Ministry of Health, after the completion a trial of the interRAI – Home Care assessment tool in the District Health Board, rolled out implementation of the interRAI – Home Care tool throughout New Zealand's 21 District Health Boards. The Quality of Life survey itself is currently being assessed and trialled throughout the world as a follow-up to the Home Care assessment. It will enable researchers and assessors to enable for a comprehensive perspective by bringing together the views of both service providers and recipients of care service. The assessments will be completed by the person directly, as a self assessment, or through interview

The overall research aim of the study itself is to evaluate the adequacy of the interRAI Quality of Life survey in assessing the Quality of Life issues and needs of the elderly living in their own homes in the community with some sort of publicly funded health care, social or community support such as meals on wheels, personal care, etc., for the purpose of demonstrating the importance of it as a useful tool within New Zealand.

The objectives of the research are as follows:

- Objective 1 - To review the management and application of quality of life indicators for the elderly.
- Objective 2 – To understand the pressures which an ageing population places on public policy.
- Objective 3 - To consider how quality of life measures can best be applied alongside interRAI in New Zealand.

The research itself focused on the Quality of Life of thirty participants. Each participant was first assessed through an interRAI – HC assessment at their own home by an assessor

from the Canterbury District Health Board. Upon completion of the assessment, they were given the option of being contacted by the researcher about participation in the interRAI Quality of Life Survey. Contact by the researcher by telephone ensued, which was then followed up by a face to face information session at the home of the participant. At this time, thirty out of thirty one potential participants decided to sign the informed consent form for participation. As the Quality of Life Survey itself is self reported, each participant was free to read through the survey and answer for themselves questions regarding their thoughts about their own quality of life.

Participants responded to forty six statements from nine different domains on the Quality of Life Survey. Overall results showed a majority of responses of 'Always', which were positive. Areas of concern which emerged from the data were of possible issues of social isolation and unresolved emotional health.

Limitations of the research included factors such as the small sample size of thirty, the geography of the study which was limited to Christchurch, and the fact that there was no follow up visit to the first and only interview.

In conclusion, it is apparent that a larger trial throughout the District Health Board is required to overcome the aforementioned limitations of sample size and geography. Also, it is imperative that a follow-up visit is scheduled after the initial visit to allow for intervention into quality of life issues which emerge from the participant's self-assessment.

Glossary of Terms

ADL – Activities of Daily Living

Age Concern – A voluntary agency serving the needs of older people in New Zealand by offering nationally contracted services, education, resources and national leadership

ADL – Activities of Daily Living

ALTCS – Arizona Long-Term Care System

CAP's – Clinical Assessment Protocols for interRAI assessment tools

CA – interRAI – Contact Assessment

CDHB – Canterbury District Health Board

CPS – Cognitive Performance Scale

DHB – District Health Board

HC – Home Care

HCBS – Home and Community Based Services

HRQL – Health Related Quality of Life

InterRAI – International Resident Assessment Instrument. A collaborative network of researchers from over 30 countries who are committed to improving healthcare for persons who are elderly, disabled or frail. (www.interrai.org)

InterRAI – HC – InterRAI -Home Care

MDS – Minimum Data Set

MEDICAID - United States health program for eligible individuals and families with low incomes and resources

MMSE – Mini-Mental State Examination

MoH – New Zealand Ministry of Health

NZGG – New Zealand Guidelines Group

NZPAS – New Zealand Positive Ageing Strategy

OECD - Organization for Economic Co-operation and Development

PHO – Primary Health Organization

POSM HCBS - Participant Outcomes and Status Measures for Home and Community Based Services

POSM NF – Participant Outcomes and Status Measures for Nursing Facility

QoL – Quality of Life

TSI – Test for Severe Impairment

UN – United Nations

WHO – World Health Organization

1.0 INTRODUCTION

1.1 Background To The Problem

Population ageing is changing the demographic profile of societies around the globe with transition from relatively high mortality and high fertility rates to relatively low mortality and low fertility rates (Dunstan & Thomson, 2006). This phenomenon is not unique to New Zealand but is a growing trend in both developed and non-developed nations (Dunstan & Thomson, 2006). The trend is currently slower in New Zealand compared to other western countries, but Statistics New Zealand shows that by 2051 the number of people aged 65 years and older in New Zealand is projected to exceed 1.33 million (Dunstan & Thomson, 2006), approximately one quarter of the total population. The changing structure of New Zealand's population is shifting from the 2006 pyramid model (see Figure 2.1) of a broad base of a younger working age population with a smaller group of supported elderly, to a more 'streamlined' age structure with similar groupings from top to bottom on the age pyramid (see Figures 2.2 and 2.3) (Dunstan & Thomson, 2006).

The growth of the elderly population in New Zealand is expected to place pressures on social and health care resources. Pressures such as a projected increase in the elderly living at home without children, projected increases in New Zealand's debt vs. increasing numbers of retirees eligible for superannuation, and projected decreases in the number of workers supporting retirees. Each of these pressures, among others, could have an effect on quality of life. Studies vary, but it has been shown to be cost effective to provide the elderly with home care options to assist them to live in their own homes, as opposed to living in residential retirement homes/long term care. This issue was addressed in papers by David C. Grabowski on the cost effectiveness of non-institutional long term care services (Grabowski, 2006), in an early paper by Susan L. Hughes at the Department of Veterans Affairs (Hughes et al, 1991), and also by scrutiny of the Arizona Long-Term Care System (Weissert et al, 1997).

Public policy and social environments can help to determine health and well-being, and social circumstances such as housing and social cohesion, can have a powerful effect on health (McGinnis, Williams-Russo & Knickman, 2002).

The New Zealand Positive Ageing Strategy was published in April of 2001 and was established to set out a commitment by the government to positive ageing (Office for Senior Citizens, 2002A). There are ten ageing goals and corresponding key action plans outlined by this policy. The Strategy:

- Aims to improve opportunities for older people to participate in the community in the ways they choose
- Provides a framework within which all policy with implications for older people can be commonly understood and developed.
- Incorporates broad guiding principals.
- Identifies ten priority goals with recommended actions. (Office for Senior Citizens, 2002A)

The vision for the Positive Ageing Strategy, set out by a reference group composed of senior citizens, states that:

“Our vision is for a society where people can age positively, where older people are highly valued and where they are recognised as an integral part of families and communities. New Zealand will be a positive place in which to age when older people can say that they live in a society that values them, acknowledges their contributions and encourages their participation” (Office for Senior Citizens, 2002A).

Some key tenets of this vision include the ability to live in a safe and secure environment, while receiving the necessary support when they can no longer live independently, having access to a continuum of health services, accessible transport to support community participation, adequate housing, and a wide range of service supports (Office for Senior Citizens, 2002A). The Positive Ageing Strategy has policy and action plans, and monitoring and review policies are in place (Office for Senior Citizens, 2002A). Integral to the Positive Ageing Policy is the concept of ageing in place, the basic premise of which is that a person has the ability and right to choose where he or she will live later

in life. Rather than having to move the elderly person into a residential facility, ageing in place believes that an older person has the right to either remain living in the community at large, such as at home with their family, in their own home of their choice, or in a supported environment if that is their choice. The Office for Senior Citizens says,

“Home is a familiar place and a treasure chest of memories. It can be an expression of one's personality, hobbies and skills. Home provides a sense of identity and a face to the community” (Office for Senior Citizens, 2009).

There are several exigencies for the concept of ageing in place to be properly implemented and maintained, such as poverty, living standards and the health requirements of the elderly. These and many others were considered by the Organization for Economic Co-operation and Development (OECD). In 1994, the OECD formulated this simple idea about the idea of ageing in place:

“Elderly people, including those in need of care and support should, wherever possible, be enabled to continue living in their own homes, and where this is not possible, they should be enabled to live in a sheltered and supportive environment which is as close to their community as possible, in both the social and geographical sense” (OECD, 1994)

The Positive Ageing Strategy, Goal 2 - Health, states an objective to “Develop options that allow integrated planning, funding and delivery of primary and secondary health services, residential care and community support services (Office for Senior Citizens, 2009). The success of ageing in place, as the ability of a person to live in their own home, can be heavily influenced by the support, or lack of it, received from community based health care and social care services. Community care providers can either be drawn from national or local levels, but when working collaboratively with health care services they can be highly effective in assisting the elderly with specific needs at home.

1.2 Responding to the Challenges of Ageing in Place and Community Care

There are many challenges to the Positive Ageing Strategy and to ageing in place. They include issues such as home based support needs, medical treatment and preventive healthcare, transportation needs, financial needs, socialisation and more. Practical issues,

such as ‘age proofing’ a home (i.e. making a home physically safe as possible for an older person), are essential but easily overlooked. Age proofing measures include ensuring that rugs and carpets are secured to flooring, keeping a list of emergency numbers close by telephones, making sure armchairs are easy to get in and out of, etc. Other, more specific, challenges for ageing in place include dealing with social isolation, ensuring comfort in the living environment (including insulation and heating), a person’s level of autonomy and control over their life, and personal relationships. Traditional family supports for ageing parents and grandparents may not be an option for people today (Anderson & Hussey, 2000). In those cases, other resources to meet their needs for ageing in place must be sought. One important aspect of an elderly person’s place within the Positive Ageing Strategy and the concept of ageing in place is the maintenance of a high quality of life. Quality of life and what that means can vary widely from one person to another and its definition is contested.

1.2.1 Quality of Life

The United Nations defines quality of life as “The notion of human welfare (well-being) measured by social indicators rather than by quantitative measures of income and production” (United Nations, 2009). Quality of life, as a concept, traverses many disciplines, from philosophy to medicine through a wide variety of social sciences (Hambleton, Keeling, & McKenzie, 2009). Indeed quality of life issues are core to the values of ageing in place and the New Zealand Positive Ageing Strategy. As it is difficult to quantify quality of life, personal preference must be taken into account with a self assessment, the most appropriate method. Self assessment allows effective measurement of a person’s needs, and a follow-up re-assessment on subsequent occasions would ensure that any quality of life issues are identified and addressed. The World Health Organisation speaks of ‘Active Ageing’ when referring to quality of life. It is the process of optimising opportunities for health, participation and security in order to enhance quality of life as people grow older (World Health Organization, 2009). Active ageing allows people to realise their potential for physical, social, and mental well-being throughout the life course and to participate in society, while providing them with

adequate protection, security and care when needed (World Health Organization, 2009). The word “active” refers to continuing participation in social, economic, cultural, spiritual and civic affairs, not just the ability to be physically active or to participate in the labour force (World Health Organization, 2009). Older people who retire from work, who are unwell or live with disabilities, can remain active contributors to their families, peers, and communities. Active ageing aims to extend healthy life expectancy and quality of life for all people as they age (World Health Organization, 2009). One specific example of a loss of active ageing, and indeed quality of life, for the elderly in Christchurch is the recent decision in March of 2010 by the CDHB to cut funding for Arthritis New Zealand gentle exercise classes for the elderly. The gentle exercise class is, for many participants, the only active exercise that they receive throughout the week. As a result, several classes throughout the calendar year will experience forced cancellations and the price per class for the elderly to attend will increase as well.

1.3 The InterRAI Assessment Tool

One tool which aids in the mission of active ageing is interRAI. The International Resident Assessment Instrument, or interRAI, was developed in the United States in 1992 by a non-profit consortium to promote the use of assessment instruments and cross-national comparisons as a foundation for improving care of the elderly, frail and disabled (Fries & Fahey, 2003). The goal of interRAI is to promote evidence-based clinical practice and policy decisions through the collection and interpretation of high quality data about the characteristics and outcomes of persons served across a variety of health and social services settings (interRAI.org, 2009). There are currently thirteen different assessment systems available through interRAI, ranging from Community Health and Assisted Living, to the Intellectually Disabled and Home Care models (interRAI.org, 2009).

1.3.1 InterRAI – Home Care Assessment Tool

The interRAI – Home Care tool has many strengths. It addresses issues such as the inter-relationship between health and disability, the problems of information duplication and omission in the assessment of older people, and the lack of consistency across settings, disciplines, and regions (Gilhooley, 2008). These strengths of interRAI are relevant to acknowledged issues in New Zealand concerning the assessment of older people in reports of the National Health Committee (2000), the New Zealand Disability Strategy (2001), the Health of Older People Strategy of (2002), the Assessment Processes for Older People (2003), and the Specialist Health Services for Older People (2004) (Gilhooley, 2008).

Although each instrument in the interRAI family of tools and applications has been developed for a particular population, they are designed to work together to form an integrated health information system. InterRAI instruments all share a common language, that is, they refer to the same clinical concept in the same way across instruments. Using common measures enables clinicians and providers in different care settings to improve continuity of care, as well as to integrate care/supports for each individual (interrai.org, 2009). Common language also allows families, advocates and public payers to track the progress of program participants across settings and over time. Such information can yield important findings regarding what works to improve an individual's quality of life (interrai.org, 2009). The reliability of the MDS was tested and proven in the paper 'Reliability Estimates for the Minimum Data Set for Nursing Home Resident Assessment and Care Screening (MDS) (Hawes et al, 1995).

InterRAI-HC has been developed to provide a common language for assessing the health status and care needs of frail elderly and disabled individuals living in the community (interrai.org, 2009). The use of this tool across the DHB in New Zealand will greatly aid in the proper assessment of older people living in their own homes.

1.3.2 A Limitation of interRAI-HC and a solution

Despite all of the advantages to nation-wide implementation of the interRAI – HC, there is one major limitation of the HC tool itself, and indeed throughout the interRAI system: that being it does not contain a specific section on quality of life. Indeed all sections within the HC tool together play a role in quality of life, but there is no specific mention of quality of life. The limitation throughout the interRAI system is that there are no self assessment tools currently available. Although the Home Care tool was developed to focus on a person's functional abilities and quality of care, information is gathered largely from the point of view of the assessor, not the person being assessed, i.e., the results may not adequately reflect the personal preferences, or views, of the older person being assessed as multiple sources are interpreted by the assessor. Also, with quality of life being such a subjective notion, it is imperative that any quality of life assessment be completed via a self administered or self assessment tool.

1.3.2.1 InterRAI Quality of Life Survey

In April 2008, Dr. John Morris presented to an interRAI conference in Barcelona, Spain, his new concept of a self assessed Quality of Life (QoL) assessment tool which would focus on the person's own perspective of their life and care experiences in the context of the care setting in which they live (interRAI, 2008). Its functional ability as a self assessment tool, when coupled with the Home Care tool, will enable for a more complete, or holistic, view of the client through a self reported survey which will "...focus on the person's own perceptions of their quality of life, in the context of the care setting in which they live" (interrai.org, 2008). It is the first tool within interRAI which is centred on the client's point of view. The assessments are completed by the person directly, as a self assessment, or through interview (interrai.org, 2008).

Regarding the QoL survey, Dr. Morris, stated that

"This is an important and ground breaking initiative for persons receiving long term care. InterRAI will be able to bring together, in the one comprehensive assessment system, the perspectives of both service providers and recipients of care services" (interRAI.org, 2008).

1.3.3 Alternative Quality of Life Assessments

Although quality of life assessments are in much greater use today than a decade ago, there is still no comprehensive assessment approach which fully covers all of the complexities and nuances that together comprise overall quality of life. Indeed, there is no agreed definition of quality of life either, as the subjective nature of the term itself leads to many different determinations, opinions and personal needs/desires. There are other QoL surveys in use today, such as the Participant Outcomes and Status Measures (POSM) which is used in Michigan, and the Multi-Attribute Health Status Classification System: Health Utility Index – 3 (HUI3). These alternate QoL systems will be reviewed further.

1.4 Research Aims and Objectives

The overall research aim is to evaluate the adequacy of the interRAI Quality of Life survey in assessing the QoL issues and needs of the elderly living in their own homes in the community with some sort of publicly funded health care, social or community support such as meals on wheels, personal care, etc., for the purpose of demonstrating the importance of it as a useful tool within New Zealand. The objectives of the research are as follows:

- Objective 1 - To review the management and application of quality of life indicators for the elderly.

- Objective 2 – To understand the pressures which an ageing population places on public policy.
- Objective 3 - To consider how quality of life measures can best be applied alongside interRAI in New Zealand.

1.5 Framework for the Dissertation

The following chapters will outline and expand upon the main objectives and aims. Section Two, New Zealand Policy Context for Ageing in Place, will outline the demographic changes which have occurred in New Zealand's, and indeed the world's, ageing population. Regarding these demographic changes, the growth of the elderly population in New Zealand and changing household profiles will be discussed. Regarding the implications of change, the pressures placed upon health and social resources will be outlined. Implicit in this discussion of health care pressures will be its effects upon New Zealand Superannuation and the workforce. Population ageing strategies will be broken down in a response to pressures, and discussion will occur regarding the various strategies themselves. The concept of ageing in place will be introduced. Integral to the discussion of ageing in place is the need to overview the determinants to successful ageing in place, and the role that QoL plays within it. Also, the cost effectiveness of home care vs. institutional care will be reviewed. Closing out Section two will be a discussion of interRAI and its role internationally and in New Zealand. Within this discussion will be a background of interRAI, its content and application in New Zealand, its limitations and an alternative approach.

Section three, Measuring and Applying Quality of Life indicators for the elderly, will overview various QoL indicators and Assessment systems, before focusing upon the interRAI QoL self assessment survey itself. Section four introduces the research methods from the study. The research purpose, protocols, and study design will be discussed. Participants and the administration of the QoL Survey will be discussed, as well as the statistical procedures used in data analysis. Section five will be discussing the research results beginning with a description of the sample, then a section by section analysis of the QoL Survey data. Finally, Section six will discuss the background of the problems

discovered and the predictors of quality of life from each section of the QoL Survey. The strengths and limitations of the study, and implications and recommendations for future policy and research will close out the thesis.

2.0 NEW ZEALAND POLICY CONTEXT FOR AGEING IN PLACE

2.1 Introduction

Currently, 13% of the New Zealand population is over the age of 65. By 2030, that number is projected to increase to approximately 21% (Statistics New Zealand, June 2009). During the June 2009 year, the population aged 65–79 years increased by 10,300 (2.6%) to reach 406,700 people. The proportion of the population aged 65–79 years was 9.4% at 30 June 2009, up from 9.0% in 1999. There was also a slight increase in the proportion of the population aged 80 years and over (80+), from 2.7% in 1999 to 3.4% in June 2009. The age group of 80+ reached 146,000 people at 30 June 2009, an average annual increase of 4,200 people (3.5%) over the decade (Statistics New Zealand, June 2009). In total, there are over half a million residents of New Zealand over the age of 65. Population ageing is an important issue fiscally as 25% of government spending is currently on the 13% of the New Zealand population aged over 65, and this will grow in the future (NZ Treasury Department, 2009).

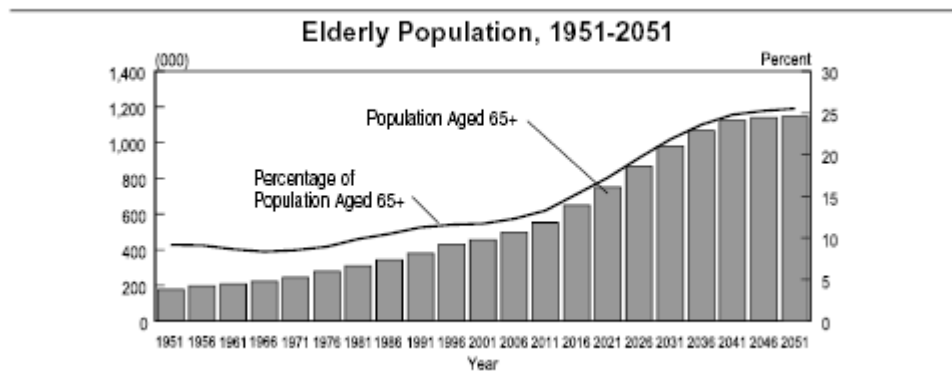


Figure 2.1 The growth of the age 65+ elderly population in New Zealand. (Statistics New Zealand, 2010)

One stressor which could occur due to an increase from 13% to 21% in the 65+ age group by 2030 is a decreased work force growth. This in all probability would lead to a decrease in the amount of workers supporting the retired, could present problems for the

viability of national superannuation, possibly lead to increases in taxes, and could ultimately affect quality of life. Many people in the 65+ age group will be retired or in semi-retirement. The future workforce will undoubtedly be an older one as well, as between now and 2051, the number of older people (those aged 45-64 years) is expected to rise from about 35% to nearly 45% of the working-age population (Alpass & Mortimer, 2007).

Another implication that the increase of the 65+ age group could lead to is a higher dependency ratio. Namely, that the growing number of retirees will increase the burden on the working population that supports them (Alpass & Mortimer, 2007). A frequently used measure of the potential burden imposed by population ageing is the dependency ratio, which refers to the number of children (0-14 years) and elderly people (65 years and over) relative to the number in the working-age population (Alpass & Mortimer, 2007). The dependency ratio is the sum of the dependent share of the population relative to the working age share of the population (Alpass & Mortimer, 2007). Regarding the future dependency ratio in New Zealand, Alpass & Mortimer concluded that:

These changes in the dependency ratio in New Zealand are clear. By 2051, it is likely that the population share of those 65 years and older will more than double, while the youngest share of the population will contract by nearly one-third.

These trends translate into a higher dependency ratio (Alpass & Mortimer, 2007).

The dependency ratio in New Zealand currently stands at approximately 0.53: that is, for every 100 people of working age (those between 15 and 64 years of age), there are 53 people younger or older (Alpass & Mortimer, 2007). The dependency ratio is projected to dip to 0.50 in 2011 before rising to about 0.71 in 2051, when for every 100 people of working age, there will be 71 people younger than 15 and older than 65 (Alpass & Mortimer, 2007). The rising dependency ratio could lower our per capita GDP growth rate (Alpass & Mortimer, 2007).

Another imminent implication of the increasingly large population in the 65+ age group are the questions concerning the viability of the national superannuation scheme. The concerns of an increasing number of retirees, a lower number of workers in the workforce,

and an increasing dependency ratio could mean financial strains to superannuation. Much discussion has occurred about the possibility of increasing the age for eligibility for national superannuation from 65 to 67. There are no indications that this will occur in the short term, but discussion and review will undoubtedly continue.

Population ageing is changing the demographics of societies around the world. New Zealand has policy initiatives in place to aid the elderly through this transition. Policy papers and initiatives such as the Positive Ageing Strategy, the Report of the National Health Committee (2000), the New Zealand Disability Strategy (2001), the Health of Older People Strategy (2002), the Assessment Processes for Older People (2003), and the Specialist Health Services for Older People (2004), will all be discussed. A key review will focus on a significant new initiative within this myriad of policy, the implementation of the interRAI – Home Care tool by the MoH, through the DHB. Further examination will focus on key concepts such as Ageing in Place and Active Ageing, which are playing important roles in ensuring for a high quality of life for the elderly.

An important and newly introduced aspect to the construct of high quality of life for the elderly is the self-assessed Quality of Life survey through interRAI. It is the first tool within interRAI which would be centred upon the point of view of the client, instead of the assessor. The efficacy and possible future role(s) of the QoL survey within the framework of elder-care in New Zealand will be reviewed. Overall, this chapter will be used to examine the many differing components which contribute to quality of life for the elderly, the QoL survey itself, and the possible future of the QoL survey within the MoH.

2.2 Demographic Change

2.2.1 The growth of the Elderly Population in New Zealand

As noted in ‘Demographic Aspects of New Zealand’s Ageing Population’, (Dunston & Thomson, 2006), population ageing can be regarded as an intrinsic dimension of a world wide demographic transition from relatively high fertility rates and high mortality rates,

to relatively low mortality rates and relatively low fertility rates. The cause of the demographic transition is rooted in various socio-economic and health factors which have reduced mortality and fertility rates over time (Dunstan & Thomson, 2006).

In New Zealand, population ageing manifests itself in changing population pyramids. Figure 2.2, (Statistics New Zealand, 2006), depicts male and female age/sex ranges for New Zealand for 2006, with estimated population age/sex ranges for the years 2021 (Figure 2.3) and 2041 (Figure 2.4). In Figure 2.2, (2006), the 65-69 age tier shows both the male and female populations as less than 2% of the total population. The 75-79 age tier is close to 1%. The population range graph of 2006 follows the trends of an increasingly ageing population reported by Statistics New Zealand since 1951 (Statistics New Zealand, 2009).

(Figure 2.2) New Zealand Age/Sex Population Distribution 2006
(Total Population 4.18 Million)

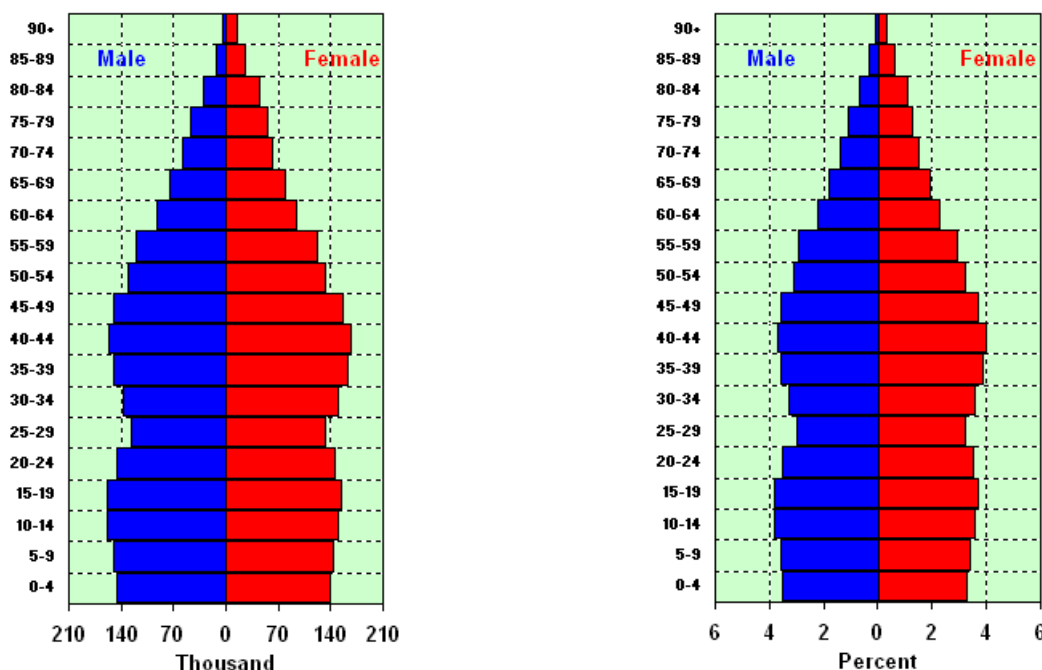
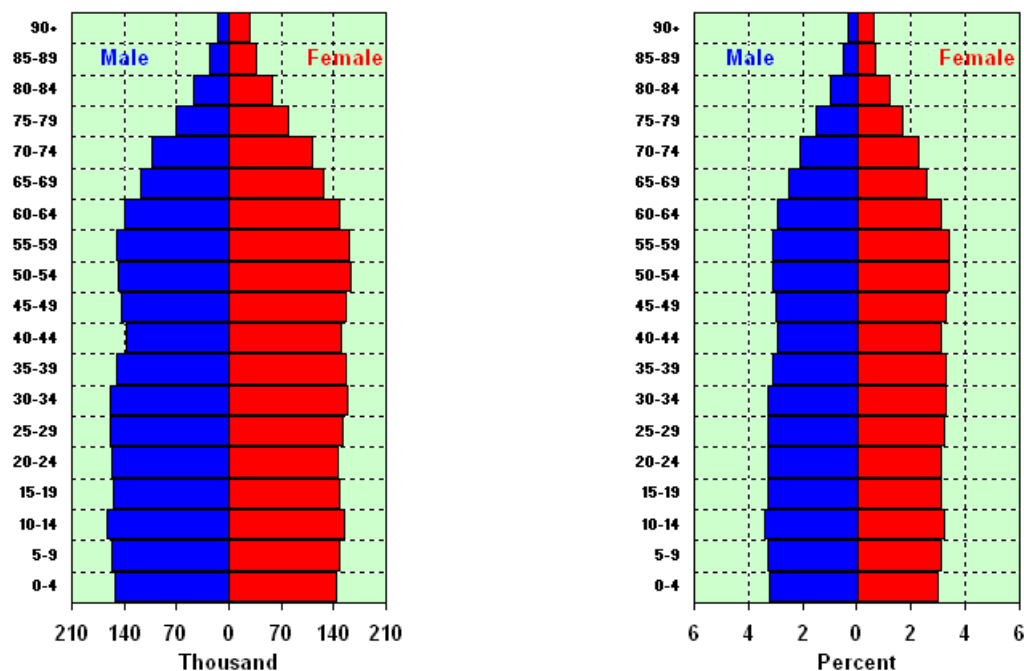


Fig.2.2 – Year 2006 population pyramids illustrate the age/sex structure of the New Zealand population. On the left side of the pyramids are five year age groups. On the bottom of the pyramids are population in either thousands, or percent.

Population estimates for 2021, shown in Figure 2.3, show that the ageing of the population is likely to continue. When compared to the 2006 model, the 2021 estimates show increases in population in all age tiers 60 and older. It is only in the 75-79 age tier that both male and female populations are each projected to be less than 2% of the total population, ten years later than the 2006 population distribution. It is only in the 80-84 age tier that both male and female numbers are projected to fall below 1% (Statistics New Zealand, 2009).

New Zealand Age/Sex Population Distribution 2021 (Figure 2.3)
(Total Population 4.77 Million)

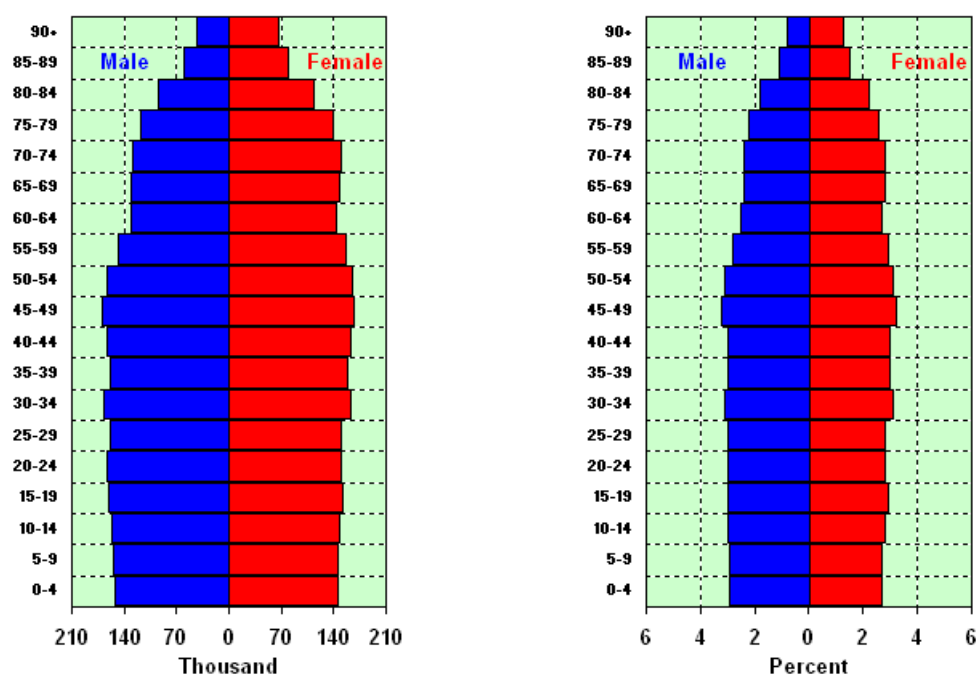


(Statistics New Zealand, 2009)

Fig.2.3 – Year 2021 age population pyramids illustrate the changing age/sex structure of the New Zealand population. On the left side of the pyramids are five year age groups. On the bottom of the pyramids are population in either thousands, or percent.

The dynamics of population ageing become clearer when looking at New Zealand's population projections for year 2041 (Figure 2.4). It is clear from the 2041 estimated data that the age tiers of 60-64, 65-69 and 70-74 are all quite similar. This is different from previous projections where there is a noticeable drop in numbers as age increases. The male age tier does not fall below the 2% range until 80-84 range, with the female tier only falling below 2% at 85-89. The male projection falls below the 1% range only in the 85-89 tier, while the female population reaches that level only at the 90+ age tier (Statistics New Zealand, 2009).

New Zealand Age/Sex Population Distribution 2041 (Figure 2.4)
(Total Population 5.33 Million)



(Statistics New Zealand, 2009)

Fig.2.4 – Year 2041 age population pyramids illustrate the changing age/sex structure of the New Zealand population. On the left side of the pyramids are five year age groups. On the bottom of the pyramids are population in either thousands, or percent.

Keeping debt under control will be vital to New Zealand's drive towards effectively dealing with an ageing population. If current policies lead to increasing debt, future generations will find it difficult to set their own spending priorities or to meet unforeseen challenges (NZ Treasury Department, 2009). High levels of public debt increase the cost to everyone through higher interest rates, debt servicing and taxes, and ultimately could limit the ability of governments to implement the ageing policies they want (NZ Treasury Department, 2009)

2.2.2 Changing Household Profiles

The number of families in New Zealand is projected to increase from an estimated 1.17 million in 2006 to 1.44 million in 2031 (Statistics New Zealand, 2008). Couples without children will account for the majority of this growth, increasing from 468,000 in 2006 to 730,000 in 2031 (Statistics New Zealand, 2008). The increasing prevalence of couples without children is mainly due to the increasing number of people born after World War II reaching older ages (50 years and over), where they are most likely to live as a partner in a couple without children (Statistics New Zealand, 2008). Most of these couples will have had children who have left the parental home. Couples without children overtook two parent families to become the most common family type in 2008 (Statistics New Zealand, 2008). The number of households is projected to increase from 1.55 million in 2006 to 2.09 million in 2031 (Statistics New Zealand, 2008). Households containing one or two people are projected to account for nearly all of this growth (Statistics New Zealand, 2008). Based upon these projections, the majority of people in households containing one or two people will invariably be in the fifty to sixty plus age bracket(s) (Statistics New Zealand, 2008). With this projected increase in the elderly living in their own homes without children, it would be wise for New Zealand to prepare for the strain that this eventuality may place on both social and health care frameworks. With an increasing number of elderly living alone in their own homes, it is important that homes are 'age proofed' for both safety and sustainability, and that quality of life is not compromised.

An important and historical aspect of long term care of the elderly is informal care, which is usually unpaid and provided by relatives and/or family members. Informal care support appears to have weakened over the last three decades. Anderson and Hussey (2000) found that the proportion of elderly persons living alone rose from 1970 to 1990, while the percentage of elderly living with their adult children had declined in the past three decades (Anderson & Hussey, 2000). In looking into the financing of long term care, Anderson and Hussey found New Zealand and the United States to have a higher proportion of private funding than other western nations surveyed (Australia, France, Germany, Japan, United Kingdom and Canada) (Anderson & Hussey, 2000).

2.3 Implications of Change – Pressures on Resources

As the elderly (65+) population of New Zealand continues to grow, the challenges of dealing with the corresponding pressures on health care resources will accumulate. Although funding to DHB has increased, many are still struggling with debt and are faced with cost savings measures. For example, Home Help assistance to the elderly has been reallocated from those deemed to have low level needs to those deemed with high level needs at the CDHB due to budget constraints. Many elderly voiced the complaint though that they felt they were being deemed low level via telephone evaluations. This has caused a level of consternation amongst those elderly whose home help hours are being either reduced or cut completely. The pressures facing health care in New Zealand with regards to the growth of the elderly population and its potential impact in the future is succinctly summed up in the report 'Report 2: The interRAI Evaluation'. The report states that older people (aged 65+) constitute 12.4% of the population, with this figure anticipated to rise to 25% by 2050 (Weidenbohm, Parsons, Dixon, Keeling, Senior, & Brandt, 2008). However, of more significance is the fourfold increase in 75+ year olds and six-fold increase in 85+ year olds anticipated to occur over the next 20 years (Weidenbohm et al, 2008). Specifically, by 2021 around 2.3% of the population will be aged 85+ (Weidenbohm et al, 2008). Given that 75+ year olds utilise three times the health care resources of other age groups the impact on health and social resources will be considerable (Weidenbohm et al, 2008).

The predicted demographic changes in the Maori population are more pressing: from 1998 to 2010, a fourfold increase in 75+ Maori will be observed. Given the incidence of age-related conditions occurring at younger ages, there are concerns over the impact of such an increase on older Maori and their whanau (Weidenbohm et al, 2008).

Increasing longevity and declining fertility rates have been shifting demographic profile of populations in all industrialized countries, including New Zealand, toward older age groups (Anderson & Hussey, 2000). The projected ageing of the workforce means that existing health models are not sustainable in the long term (Gordon, 2009). Mary Gordon, former interim Chief Executive of the CDHB, had these comments to say about the projected ageing of the workforce, health care service, and the future sustainability of health care in Canterbury, New Zealand:

If we continue to provide the same level of care in the same way as we do today then by 2020 we will need another hospital the size of Christchurch Hospital, 2000 more aged care beds and 20% more GPs. Obviously this is not sustainable. Thus we need to look at how we can provide services that are patient/family centric that remove unnecessary waste, duplication and standardise care to ensure that we best use the health resources we have (Gordon, 2010).

It is not hard to extrapolate Ms Gordon's comments throughout the DHB. The CDHB has presented a report that showed their financial result for December 2008 was a deficit of \$3.685M, which was \$2.598M unfavourable against the budgeted deficit of \$1.087M (Gordon, 2009). This has been viewed as concerning and unsustainable for the long term (Gordon, 2009). Ms Gordon commented that the key drivers of this deficit were: Community Pharmacies, Special Foods, Aged Care, Medical/Surgical, and Women' and Children's acute activity (Gordon, 2009). Responding to these concerns, David Meates, the Chief Executive of the CDHB noted:

The national fiscal situation has deteriorated over the last few months. Health is in a position where they have certainty of funding and we need to be very disciplined as to how we bring our spending in line with this. We need to ask ourselves are there more efficient and effective ways of providing our services?

We also need to be very much focused on how we deal with growing demand and pressures on health within the constraints imposed (Meates, 2009).

Another significant contributor with regards to the pressures placed on resources is the decreasing age of retirement in New Zealand. The age of retirement has important public policy implications for two reasons; first, it increases the number of retirees, and second, it reduces the number of workers that are contributing to public programs financed through workers' contributions and taxes (Anderson & Hussey, 2000). Both have the potential to significantly affect health care, economic, and social resources. Anderson and Hussey's study found that in New Zealand, the average age of retirement for women had decreased from 62.5 in 1960 to 58.6 in 1990, while in men the retirement age decreased from 65.1 in 1960 to 62 in 1990.

Across many OECD countries, the trend over the past 30 years has been for people to retire at a younger age, despite evidence of improvements in life expectancy (Hurnard, 2005B). This trend can be seen in generally falling rates of labour force participation among males in the age group 55 to 64 years, as shown in Figure (Hurnard, 2005). In their research programme on social security programmes and retirement around the world, Gruber and Wise (2002) comment that the decline in labour force participation of older persons is perhaps the most dramatic feature of labour force change over the past decades (Hurnard, 2005A).

Figure 2.5- Proportion of males aged 55-64 who are in the labour force

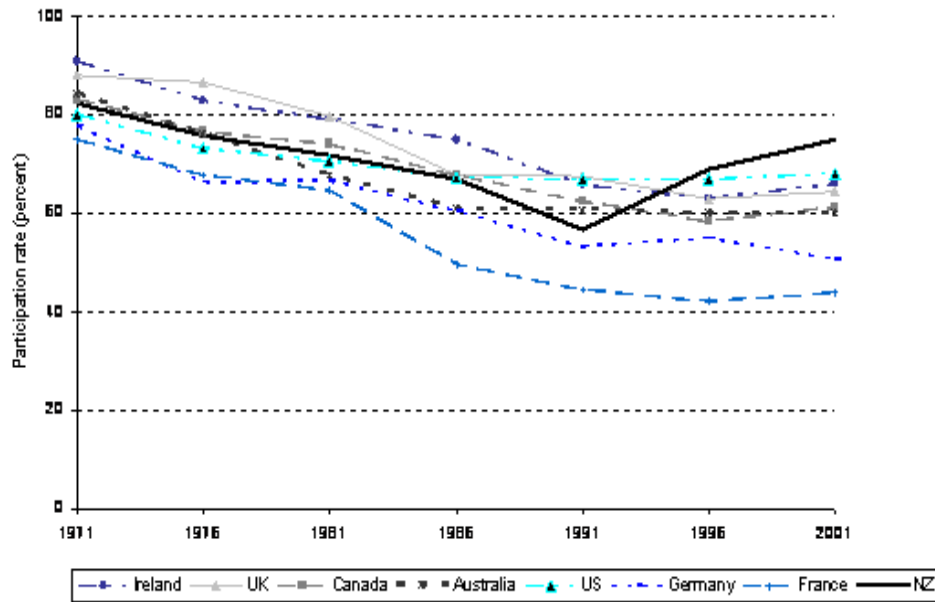


Figure 2.5 shows that the experience of New Zealand stands in contrast to that of other Countries (Hurnard, 2005B). The decline in labour force participation rates of older males that New Zealand shared with other OECD countries over the period 1971 to 1991 was reversed over the subsequent 10 years as New Zealand changed from experiencing a participation rate that in the earlier period was about average among the comparator countries shown in Figure 2.6 to one that, by 2001, was clearly higher than all the other comparator countries (Hurnard, 2005B). A similar pattern of divergence between New Zealand and other OECD country participation rates has occurred since 1991 in the case of older females, but in this case it has overlaid a generally rising trend of female participation (Hurnard, 2005A). Hurnard argues that the primary reason for the New Zealand sharp turnaround in older people's labour force participation since 1991 was the phased increase in the eligibility age for the public pension, the National Superannuation Fund, from 60 to 65 years, which commenced in 1992 (2005A). The delayed eligibility to superannuation has resulted in many people delaying their retirement from the paid work force (Hurnard, 2005A).

2.3.1 New Zealand Superannuation

New Zealand Superannuation provides a source of income to people who have reached a qualifying age (currently 65 years) and who meet other eligibility criteria, such as residency (Ministry of Social Development, 2008). The issue of increasing the age for eligibility for superannuation in New Zealand has been contentious during the current world wide economic downturn. Proponents of increasing the age for eligibility from the current 65, to 67, point to recent predictions by the New Zealand Treasury Department that the net public debt could rise by 220% in the next forty years (NZ Treasury Department, 2009). Table 2.1 outlines the increase in the number of people who are receiving national superannuation for the years of 2004 through to 2008. The 2008 total represents an increase of approximately 10.7% from 2004.

Age of client at the end of June	People receiving New Zealand Superannuation				
	2004 Number	2005 Number	2006 Number	2007 Number	2008 Number
Under 60 years	4,507	4,205	3,899	3,484	3,179
60-64 years	12,815	11,971	11,072	10,303	9,781
65-69 years	127,786	135,322	144,867	153,900	158,186
70-74 years	111,757	111,329	111,240	113,201	117,332
75-79 years	94,098	95,021	96,754	97,382	97,581
80 years or over	113,661	117,367	120,993	124,447	128,217
Total	464,624	475,215	488,825	502,717	514,276

Table 2.1- Trends in the ages of clients receiving New Zealand Superannuation (Ministry of Social Development, 2008)

At the Workshop on Labour Force Participation and Economic Growth on 14 April 2005, Roger Hurnard concluded that if in 1991 the eligibility age for National Superannuation had been 65, not 60, the labour force participation of males aged 60-64 would have been almost 60 percent instead of under 40 percent, while the labour force participation of females aged 60-64 would have been over 30% instead of 17%, assuming they would have shared in the rising participation trend of working age females (Hurnard, 2005).

The current age of eligibility for New Zealand Superannuation is 65, the same as the age of eligibility for the first New Zealand age pension, introduced in 1893 (NZ Treasury Department, 2006). The adequacy of retirement savings has become an important issue with the dual factors of the 2009/10 economic downturn and the ageing of the NZ Population. It has been calculated that raising the eligibility age for National Superannuation to 67 could result in savings of at least \$100 Billion by 2061 (Mercer.co.nz, 2010). The Government is under pressure to make a change in qualifying age for superannuation to help to pay for our ageing population after deciding that it could not afford to pay into the New Zealand Superannuation fund for the next 11 years (Beehive.govt.nz, 2009B) In a dissenting opinion, Age Concern national President Liz Baxendine believes that an alternative to raising the age of eligibility is necessary:

Calls to raise the Superannuation age to 67, or even higher, ignore the situation of manual workers, Maori and Pacific people. After a lifetime of work and paying taxes they would receive less benefit if the Super age was raised because they tend to die earlier. We all need to plan for a future with one million older New Zealanders, but we need to do it without talking about the 'burden' of older people (Baxendine, 2009).

Many countries have, or are planning on increasing the age for pension schemes, including

- Australia's Labour Government decided in May of 2009 to raise the qualifying age for its means-tested pension from 65 to 67 in steps between 2017 and 2023 (nzherald, 2009).
- The United Kingdom announced in a 2006 White Paper discussing their new pensions system that they will gradually increase their State Pension age from 65 in 2024 to 68 in 2046
- Denmark is increasing the age threshold for the public old age pension from 65 in 2024 to 67 in 2027. Furthermore from 2025, the eligibility age will be directly linked to changes in life expectancy at age 60
- Japan is increasing its age for access to the earnings related component of its pension from 60 to 65 by 2025 for males and by 2030 for females (OECD, 2007).

Prime Minister John Key has said that the National led Government is absolutely committed to maintaining current eligibility rules for National Superannuation (Beehive.co.nz, 2009A). This raises the possibility of increases in taxes or GST to fund future superannuation payments. With many elderly already living on tight budgets, the possibility of a shortfall in their future pensions, or increases in taxes and/or GST is a frightening prospect, and one which could ultimately be a calamity for their own quality of life.

Auckland University economics professor Susan St John believes that a discussion concerning raising the age of eligibility is inevitable. It should start sooner rather than later, she said. "It will mean that paying New Zealand superannuation, regardless of the New Zealand super fund, will become more expensive over time and whatever we pay out will be at the opportunity cost of what else we could have done with that money," she said. Estimates show that the ageing population will push up superannuation costs from the current 4 per cent of gross domestic product to 9 per cent by 2020 (stuff.co.nz, 2009).

2.3.2 Years in the Workforce and the Corresponding Pressures Placed

In their study on population ageing, Anderson and Hussey (2000) found that in New Zealand, only 3.3% of the workforce was over the age of sixty, compared to 12.5% in Japan, 5.8% in the United States and 2.5% in France. Anderson and Hussey also reported the average amount of time spent in and out of employment from within the 29 members of the OECD. In 1960 men worked outside the home for the majority of their lives (fifty out of sixty eight years), while in 2000 men were expected to spend an equal number of years working and not working outside of the home (thirty seven years each) (Anderson & Hussey, 2000). By 2030, OECD projections show that by 2030 men will work for less than half of their lives (thirty three out of seventy six years) (Anderson & Hussey, 2000). Data for women show an increasing number of time worked outside of the home from 1960 to 1990, with numbers levelling off in the early 2000s.

Overall, this represents a decrease in the number of working age people to support those in retirement. The elderly are currently experiencing a decreasing age of retirement, an increase in longevity, a decrease in the numbers of elderly living with their adult children, and a high percentage of private funding spent on long term care financing. One additional and important statistic to add to these is the number of workers who are currently supporting retired pensioners. In 2000, there were approximately four to six workers for every person aged 65 or older. Between 2000 and 2020 that number will decrease to two to four potential workers for every elderly person (Anderson & Hussey, 2000)

This is relevant to the issue of quality of life as funding for both social and health care programs for the elderly who are living in their own homes could be affected by monetary shortfalls. A media report (Christchurch Press, 15 August 2009) entitled ‘Home help in spotlight’ outlines probable cuts in health care programs.

Home help for some elderly will be cut and fewer people will be funded to live in rest homes as the Canterbury DHB reviews its “unsustainable” aged-care services. People receiving aged-care services such as district nursing or home help would be reassessed, which could result in cuts to the services for some, but more help for others. Chief Executive David Meates stated that “This is not sustainable and the current rate of increase puts funding for other board services at risk” (The Press, 2009).

Many studies have been carried out on the cost effectiveness of home based programs for both health care and various social welfare programs. Section 2.4.3 will review some of these studies. It is important that we realize the potential that these programs have to both maximize cost savings to an already stressed health and social welfare budget, but also their ability to provide a greater quality of life for our increasingly elderly population. Given that we are able to sufficiently predict the growth of our 65+ age population, public policy should be able to prepare now for this eventuality.

2.4 The Response

2.4.1 Positive Ageing Strategy

The New Zealand Positive Ageing Strategy (NZPAS) was promulgated by the MoH in 2001 as a way to set out the Government's commitment to positive ageing. The NZPAS aims to improve opportunities for older people to participate in the community in the ways they choose, by providing a framework within which all policy that has implications for older people can be commonly understood and developed by incorporating broad guiding principals, and by identifying ten priority goals with recommended actions (Office for Senior Citizens, 2002A). The ten priority goals cover income, health, housing, transport, safety and security, culturally appropriate services, rural communities, positive attitudes to ageing, employment, and opportunities for community participation.

The Positive Ageing Strategy establishes a set of principles as a framework for integrating policies and programmes across the government sector, but can be seen as a living document that is a basis for action (Dalziel, 2001). There are ten positive ageing principles and ten priority goals, both of which contribute to and reinforce the value and commitment which the former government showed towards the elderly in New Zealand. The current Minister of Senior Citizens, John Carter MP, has identified changing attitudes about ageing as a priority (johncarter.co.nz, 2010). He spoke to the New Plymouth Ageing Trust about his priorities regarding Positive Ageing:

It's about promoting the contributions older people make to their communities, while encouraging older people to continue to stay involved. Our contribution and value to society don't end when we stop work – there are many ways we can stay involved and continue to give. These can include working with groups like the New Plymouth Ageing Trust, other groups like Rotary or Lions, and helping out at local schools. Being involved, being seen, and having something to give helps change the younger generation's attitude towards what it means to age (johncarter.co.nz, 2010).

These words are clearly in line with the principles of the NZPAS. As noted in the executive summary of the NZPAS,

“Older people are important members of society and have the right to be afforded dignity in their senior years; They have skills, knowledge and experience to contribute to society, and the expected growth in the proportion of older people during the coming decades will provide New Zealand with a valuable resource. Further, continued participation in older age has benefits for the individual concerned, the community, and the country as a whole” (Office for Senior Citizens, 2001).

Of the ten principles which guide the NZPAS, a common theme throughout is the emphasis on enabling for a higher quality of life for the elderly. The ten principles of the New Zealand Positive Ageing Strategy are as follows:

- Empower older people to make choices that enable them to live a satisfying life and lead a healthy lifestyle
- Provide opportunities for older people to participate in and contribute to family, whanau and community
- Reflect positive attitudes to older people
- Recognise the diversity of older people and ageing as a normal part of the lifecycle
- Affirm the values and strengthen the capabilities of older Maori and their whanau
- Recognise the diversity and strengthen the capabilities of older Pacific people
- Appreciate the diversity of cultural identity of older people living in New Zealand
- Recognise the different issues facing men and women
- Ensure older people, in both rural and urban areas, live with confidence in a secure environment and receive the services they need to do so
- Enable older people to take responsibility for their personal growth and development through changing circumstances

All ten of these Positive Ageing principles deal, in one way or another, with the issue of quality of life. The definition of ‘quality of life’ is itself one which is subject to much individual and social interpretation and opinions. Several principles of the Positive Ageing Strategy, especially “Empower older people to make choices that enable them to live a satisfying life and lead a healthy lifestyle”, “Ensure older people, in both rural and urban settings, live with confidence in a secure environment and receive the services they

need to do so”, and “Enable older people to take responsibility for their personal growth and development through changing circumstances”, can all be related directly to the ability to remain living in one’s own home. Empowering, Ensuring and Enabling the elderly of New Zealand to live higher quality of lives at home is directly in line with the Ministry of Health directive on the Positive Ageing Strategy.

2.4.2 Ageing in Place

Ageing in place is defined by the Centres for Disease Control and Prevention as the ability to live in one’s own home and community safely, independently, and comfortably, regardless of age, income, or ability level (CDC, 2009). An important initial aspect in the definition of ageing in place is that of choice. It is the choice of most older people to remain living in their own home for as long as possible (Office for Senior Citizens, 2002B). Recognising the wishes of older people and the economics of providing care and support, central government has responded with an ageing in place policy framework (Office for Senior Citizens). The goal of ageing in place is to support people to remain living in their own homes as long as possible (Office for Senior Citizens, 2002B). This is done through a range of programmes within the disability support services currently administered by the Ministry of Health (Office for Senior Citizens, 2002B). Programmes include:

- *Home help services (cooking, cleaning, etc) without cost to Community Services Card recipients who have been assessed as requiring that assistance. People who do not have a Community Services Card are expected to pay for their own household management services.*
- *Home support services that offer personal care (for example bathing and showering) to people who require such assistance. Recipients of these services are not subject to financial means testing*
- *Other forms of assistance such as wheelchairs and aids, appliances and equipment that enable the person to remain in their own home (Office for Senior Citizens, 2002B)*

Judith Davey, of the New Zealand Institute for Research on Ageing, wrote extensively about the concept of ageing in place in her paper ‘Ageing in Place: The views of older homeowners on maintenance, renovation and adaptation’. Davey explains that “Internationally it has become accepted that traditional institutional care that keeps older people apart and medicalises old age is no longer desirable and perpetuates a negative view of ageing” (Davey, 2006). Most OECD countries are committed to reducing the number of people living in institutions (OECD, 1994). The ageing process should no longer be viewed as the inevitability of economic and social isolation from the rest of the community. Ageing in place should imply that older people will, whenever possible, remain in the community, either in their family homes, in homes to which they have moved in middle or later life, or in supported accommodation of some type, rather than moving into residential care (Davey, 2006). In 1994, the OECD issued its core aim of policy directed at the care of the frail and elderly:

Elderly people, including those in need of care and support should, wherever possible, be enabled to continue living in their own homes, and where this is not possible, they should be enabled to live in a sheltered and supportive environment which is as close to their community as possible, in both the social and geographical sense (OECD, 1994)

2.4.2.1 Determinants of Successful Ageing in Place

Establishing the determinants for the successful implementation of ageing in place is an important aspect in seeing it through. The first and obvious determinant is housing.. Many elderly inevitably move from larger homes to smaller and easier to manage homes, ie over 60 homes, as they enter their ‘golden’ years. A recent study by the American Association of Retired Persons revealed that 89% of homeowners over the age of 45 prefer to remain living in their own homes, yet 80% of the population will require special housing needs at some point (Squidoo, 2010). Many ageing in place schemes use housing designs and renovations which allow the elderly to remain living in their homes longer by including renovations such as eliminating stairs by installing residential elevators, widening doors and hallways for wheelchair and/or walkers, installing easy to use light

switches and door handles, and designing custom bathrooms for residents with limited mobility (Davey, 2006). Many elderly who wish to remain in their long term family homes consider adaptations to make it possible to live with physical and/or health related limitations. Adaptations can be determined through an assessment from a qualified assessor. Indeed, a vital part to the solution of successful ageing in place is a robust and consistent assessment system. An option for the elderly who might be living in a hard to manage home is to have an assessment of their situation via a qualified home care assessor. Through this visit the elderly person or couple can receive assistance in determining what modifications their home requires for them to remain living at home safely.

A second determinant to successful ageing in place is having a plan in place to empower your ability to make informed and timely decisions. The focus of your plan should be control; control of your environment, your care, your dignity, your comfort and your quality of life (ageinplace.com, 2008). The primary goal should be to create a plan that enables you to stay in your home as long as you are able, ensures your needs are met and supports your independence (ageinplace.com, 2008). A third important determinant to successful ageing in place is the proper management of finances. Jeff Helms, a certified retirement coach, has identified five key risks which the elderly will be faced with:

- **Outliving Your Assets** - The new generation of retirees will live longer than any other generation in human history. In 1970, the average age of retirement was 65, with the average person living to around the age 72. Today, the average age of first retirement is 58, with many people living into their 90s. The amount of time spent in retirement has almost quadrupled and many people are not prepared for it. The average person plans for just 19 years of post retirement living. Ensuring that assets are positioned to support retirement for the long haul should be a critical element of planning.
- **Inflation** - Inflation is defined as the rise in cost of goods and services. When people were, on average, retiring at 65 and dying at 72, a 3% annual inflation rate was not concerning. However, 30 years in retirement with a 3% inflation rate is a

- different picture. If inflation averages 3% for 25 years, the average person will need twice as much money to maintain the current standard of living.
- Poor returns - In the past, conventional wisdom dictated that you place a majority of assets in “safe” investments like CDs and bonds upon retirement. These investments typically carry lower returns due to their focus on preserving principal. But, when you factor in inflation, taxes, and a reasonable rate of withdrawals, these instruments may not last for a 30 year retirement. Investment returns that at least offset inflation and taxes are a critical component of any long term retirement strategy.
 - Healthcare expenses - The Centre for Retirement Research at Boston College projects that by 2030, as much as 35% of after tax dollars could go to support the healthcare needs of the elderly. The elderly will therefore need to ensure that they have adequate primary healthcare plan(s) and a long term care strategy in case long term care is needed
 - Taxes - The traditional notion held that taxes would be lower in retirement than in working years. Based on the current state of the economy and the budget deficit, this may be faulty thinking. Tax bills will need to be carefully managed in the future through prudent strategies to pay as little in taxes as is legally required. (ageinplace.com, 2008)

2.4.2.2 The Role of Quality of Life within Ageing in Place

What role does quality of life play within the concept of ageing in place? An important, albeit objective, notion is the inherent quality of life one receives from living in and owning one's own home. In June of 2007, Age Concern New Zealand offered a submission to the Commerce Committee on the inquiry into housing affordability in New Zealand. Age Concern submitted that:

...a majority of older persons who own their own home are able to survive comfortably off NZS (New Zealand Superannuation) as their sole source of income. This is advantageous for older persons and is a pattern that will not be repeated for later generations if the decline in home ownership continues. Older

persons in rental housing are facing higher rental prices due to the increase of house prices. Those older persons relying on NZS alone have a lower standard of living (and quality of life) and have significantly less security than those in home ownership. Age Concern draws your attention to the Living Standards research recently completed by John Jenson of the Ministry of Social Development; it has persuasive findings that suggest home ownership to be a desirable safeguard for good living standards (and quality of life) in later life (Age Concern NZ, 2007).

In the same submission, Age Concern NZ also noted that:

The government strategy of ageing in place is relevant to older persons owning their own home. Housing is a subject of great importance to the strategy; it is also inextricably linked with income and health because where you live has such a powerful influence on your life. As people grow older their needs change; in many cases their health deteriorates, often to the extent of disability in later life. The ageing in place strategy aims to reduce the social isolation that typically affects older persons forced to move from their home due to changes in their health or care needs. Age Concern asks whether those who rent are less likely than those who own to remain in their communities when their health or care needs change. Does it mean entering a rest home earlier for those in rental housing?" (Age Concern NZ, 2007)

Certainly the question about renters moving into rest homes earlier than those who own their own homes is a viable one, and one which lends credence to the importance to which home ownership holds within QoL and of course the ageing in place scheme.

A second role that quality of life plays in the concept of ageing in place is that of the promotion of independence, dignity and control over one's own life. With the inception of the Health of Older People Strategy in 2002, many ageing in place services and programmes have been developed to support the elderly who choose to remain living in their own homes. According to the MoH, The primary aim of the Health of Older People Strategy is to develop an integrated approach to health and disability support services that is responsive to older people's varied and changing needs (MoH, 2002). Ageing in place services that give older people the ability to make choices in later life about where to live,

and to receive the support needed to do so are a key component of meeting the aims of the Strategy (Ministry of Health, 2009). In the October of 2002 issue of the New Zealand Institute for Research on Ageing (NZiRA), Judith Davey wrote that “The promotion of independence and ageing in place are central to the concept of positive ageing. Even in very late life, a majority of people live in their own homes, and want to remain there for as long as possible. Entry into residential care is frequently equated with loss of independence - defined in a variety of ways (NZiRA, 2002). There are many ways that a person can prepare themselves, or their families, for ageing in place. Important preparations include:

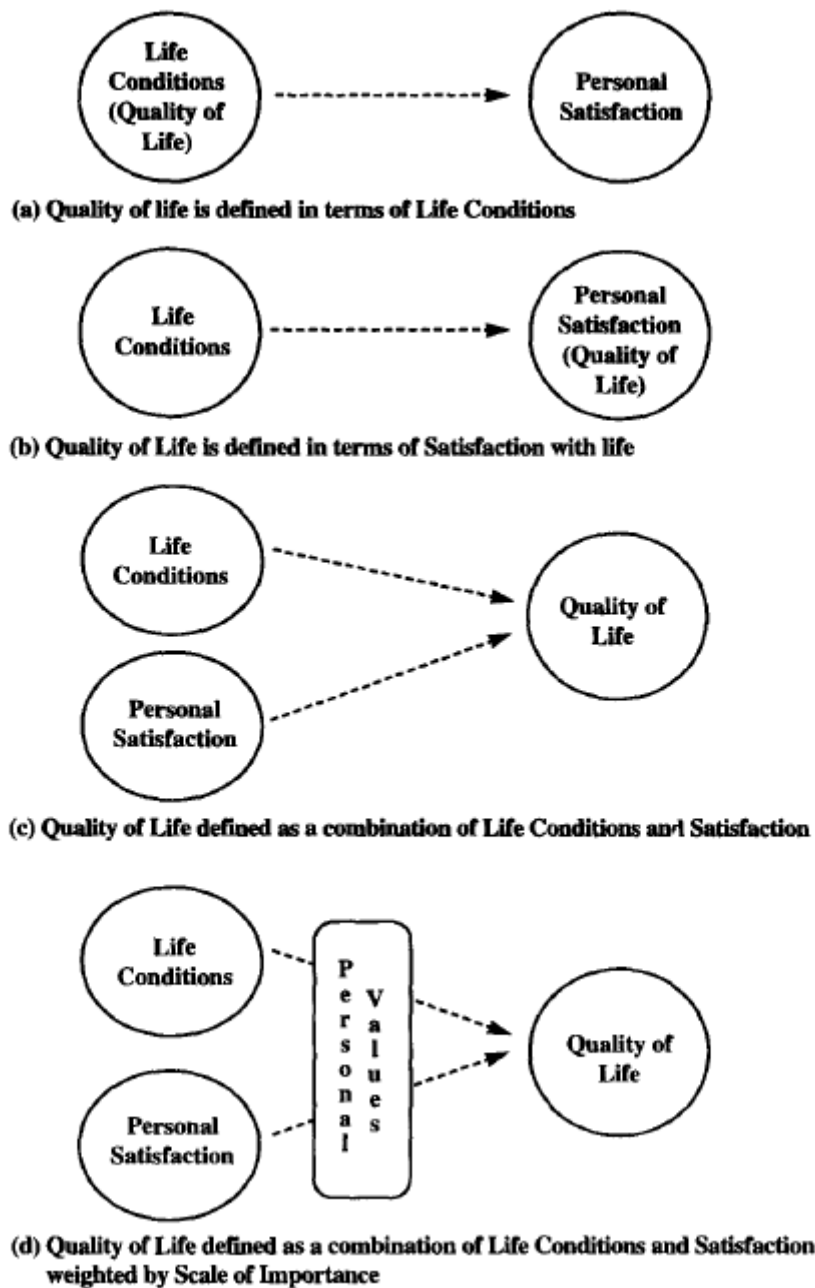
- *Think about what you want your life to be like and balance that with the reality of your current situation.*
- *Research what successful ageing in place will take. There is plenty of information available online*
- *Make a list of the type of help you might need (financial advisement, legal planning, long-term care, etc.) and locate professionals that can help you with these items.*
- *Begin identifying the items that are currently achievable, such as legal or financial planning, home modifications or others as your situation dictates.*
- *Start building your plan in timeline form and commit to dates. Fill in as you learn more and put completion dates on things. Make the commitment to yourself to finish it. (Kind, 2009)*

These preparations will go a long way to ensuring that the elderly person is thoroughly prepared to age in place, if they wish to do so. An accurate and thorough assessment system is vital to achieving successful ageing in place. These assessments and preparations can ensure for some semblance of control in the life of an ageing person living at home. In the end, requirements for successful ageing in place come down to basics such as appropriate and affordable housing, consistent and robust assessment services, the availability of support services, appropriate and affordable health care, and quality of life issues such as those provided by long standing social interactions and groups.

Thirdly, as QoL is so important to the concept of ageing in place, it is important to define what it means. QoL is an elusive concept approachable at varying levels of generality from the assessment of societal or community wellbeing to the specific evaluation of the situations of individuals or groups (Felce & Perry, 1995). Felce and Perry defined quality of life as something which integrates both objective and subjective indicators, a broad range of life domains and individual values (Felce & Perry, 1995). Concerning quality of life, Derek Gregory explains in the Dictionary of Human Geography that “The term quality of life is used to evaluate the general well-being of individuals and societies” (Gregory et al, 2009). He also states that QoL should not be confused with the concept of standard of living, which is based primarily on income. Instead, standard indicators of the quality of life include not only wealth and employment, but also the built environment, physical and mental health, education, recreation and leisure time, and social belonging (Gregory et al, 2009). Pinning down one definition for QoL is difficult due to the many and varying uses and populations for which the term could be used for. A third, and commonly used, definition for quality of life is that of the health related quality of life. Kamphuis et al, in their paper ‘Health related quality of life and health status in adult survivors with previously operated complex congenital heart disease’ wrote that, although there is no universal definition for health related quality of life, there is growing consensus that it should be assessed multi-dimensionally, including physical health, psychological state, and social relationships. Moreover, quality of life and health status are distinct constructs; quality of life is determined not only by the patient's health status problems but also by the emotional response to these problems (Kamphuis et al, 2002). The exclusive use of a definition of health related quality of life though may not be appropriate for everyday use for the adult living in their own home. Felce and Perry believe that the true model of quality of life takes into account concerns that externally derived norms should not be applied without reference to individual differences (Felce & Perry, 1995). Figure 2.5 uses a simplistic model to conceptualise four different views of quality of life. Figure 2.5(a) defines quality of life as the quality of one’s life conditions, largely an objective view of QoL. In 2.5(b), quality of life is defined as one’s satisfaction with life conditions. IE, a person may only make minimum wages at employment, but said persons QoL may or may not be adversely affected. In 2.5 (c), quality of life is

defined as a combination of both life conditions and satisfaction (Felce & Perry, 1995), a combination of objective and subjective components of QoL. Figure 2.5(d) similarly depicts quality of life as a combination of life conditions and satisfactions, but also emphasises the need to take into account the personal values, aspirations, and expectations of people themselves (Felce & Perry, 1995). Clearly the idea of defining quality of life is one that is fraught with varying ideas of subjective and objective indicators, various social and economic influences, health status, spirituality, etc. and their importance to the concept itself

Conceptualisations of Quality of Life (Figure 2.6)



(Felce and Perry, 1995)

Fig.2.6 – Four different formulations and models for Quality of Life.

2.4.3 Cost Effectiveness of Home Care vs. Institutional Care

The view that it is cost effective to provide home based community, social and health care support as opposed to institutional care, has been challenged and debated. In an early study of the terminally ill at the Department of Veterans Affairs in the United States, approximately 171 patients with informal caregivers were screened for cost effectiveness, patient functioning, and patient and caregiver morale and satisfaction (Hughes, Cummings, Weaver, Manheim, Braun, & Conrad, 1991). Findings included no differences in activities of daily living, cognitive functioning, or morale, but a significant increase in patient and caregiver satisfaction with care in the home care group. Those in the home care group used 5.9 fewer hospital days, resulting in a 47% per capita saving in hospital costs. Overall, the home care group had a total per capita health care cost that was 18% lower (Hughes et al., 1991).

Weissert et al (1997) scrutinized the Arizona Long-Term Care System (ALTCS) for Medicaid savings. The ALTCS promotes the integration of home and community based services programmes (HCBS) and provides institutional, residential, and in-home services to elderly and disabled Medicaid recipients who meet the criteria for placement in a nursing facility (Riley & Mollica, 1996). The intent of ALTCS is to lower long-term care costs by replacing institutional care with home based care (Weissert et al, 1997). The payment structure of ALTCS creates opportunities for contracted health care providers to serve members in their own homes or in residential settings rather than in nursing facilities (Weissert et al, 1997). Regular monitoring, case management oversight, and member satisfaction surveys assure that services are provided when needed in a cost-effective manner. As a result of the programmes success, an initial maximum of 5% of the number of members who could receive its home and community-based services, imposed at the program's inception in 1989, was increased to 40% in 1995 (Riley & Mollica). Despite this expansion of home and community care, an independent evaluation found that ALTCS expenditures were 17% lower than would have been incurred in a fee-

for-service system (Weissert et al, 1997). Estimates of savings were very robust and did not appear to be declining as the program matured (Weissert et al, 1997).

One area of saving was due to the assessment teams, which judged client eligibility, being employed by the State of Arizona and independent of the program providers (Weissert et al, 1997), thus removing the possibility of conflict of interest. Currently, interRAI – Home Care assessors working within the CDHB are similarly independent of the various contracted providers that provide home health, social and community based support to those elderly in need. InterRAI assessors are employed by the DHB not private contractors, PHOs or other health care agencies. Largely, the ALTCS provides savings through three variants: (i) its adoption is State-wide not random which allows for continuity, (ii) there is a particularly strong preadmission screening process, (iii) the effort to contain HCBS spending (Grabowski, 2006). The ALTCS provides structured capitated payment rates to the program contractors, or managed care organizations, for all eligible persons within a certain geographic area. The program contractor receives the capitated rate and assumes responsibility for writing a care plan, determining the appropriate level of care, arranging home care services or institutional placement, and paying for all care (Weissert et al, 1997). The program contractor is at risk for managing health care and all other costs so that aggregate expenses for their covered population fall slightly below per-capita payments (Weissert et al, 1997).

The ALTCS program found significant savings, high quality of care and patient satisfaction, and better processes of care (Weissert et al, 1997). ALTCS beneficiaries were less likely than those in the control group to be hospitalised, to have an inpatient professional visit, to have a procedure, and to have a laboratory service (Weissert et al, 1997). Overall, the capitated system of ALTCS decreased many costly procedures and increased evaluation and management services (Weissert et al, 1997). In comparing actual and projected costs, the ALTCS was estimated to save 35 percent of projected nursing home costs, or \$4.6 million dollars over the 24 month period of study (Weissert et al, 1997). Weissert et al found that the ALTCS provided the best evidence to date that capitation can potentially save program resources (Weissert et al, 1997).

In his paper on the cost-effectiveness of non-institutional long-term care services, David C. Grabowski wrote that:

“Public financing of long-term care has historically favoured institutional care over non-institutional care. However, there has been a great deal of interest in expanding home and community based services (HCBS) during the past two decades. The economic rationale for this expansion is based largely on two ideas. First, individuals generally prefer care in the home or community [rather than] a nursing facility. And second, for many individuals with less intensive care needs, it is possible to provide lower per capita cost care in the home or community relative to a nursing home” (Grabowski, 2006).

The conceptual framework for the cost effectiveness of long-term care services for non-institutional adults is bound in their preference for care in their own home or community, and in the fact that individuals with less intensive care needs can be provided with lower per capita cost care in the home or community relative to care provided in a nursing facility (Grabowski, 2006). Early studies comparing home and community based services (HCBS) to nursing home care found that HCBS reduced nursing home use, but increased aggregate long term care spending because the small decrease in nursing home utilisation observed under HCBS was more than offset by increased HCBS spending on individuals who would not have entered a nursing home even in the absence of HCBS programs (Grabowski, 2006). In terms of effectiveness, very few studies based on randomized experimental designs found statistically significant differences between the treatment and control groups in either survival or physical and mental functioning (Grabowski, 2006). In subgroup analyses, patients who were younger, less disabled, and socially supported were found to benefit from HCBS (Grabowski, 2006). Importantly, studies generally supported the idea that psychosocial outcomes such as life satisfaction, social activity, social interaction, and informal caregiver satisfaction were higher under HCBS (Grabowski, 2006). Moreover, there was evidence that the number of unmet needs decreased under HCBS (Grabowski, 2006). One way to address the issue of cost is through a capitated payment arrangement in which providers receive a flat fee for each individual enrolled in a managed health care plan (Grabowski, 2006). In theory, this

arrangement should encourage lower overall utilisation of services, which might also entail relatively more HCBS and less nursing home care (Grabowski, 2006). This is similar to the structured payment system that managed care organizations in Arizona receive through the ALTCS. It is also important to note the difference between cost analysis and cost effectiveness. In cost analysis, the focus is strictly upon the cost, and in the latter, differences in costs are benchmarked against differences in effectiveness (Grabowski, 2006). Effectiveness may include such dimensions as health and functioning, longevity, unmet needs, satisfaction with care, informal caregiver (e.g., spouse) support, life satisfaction and morale, and the degree of social interaction (Kemper, Applebaum, and Harrigan, 1987). Thus, even if care provided from HCBS is associated with higher aggregate costs, the services may still be cost effective because of an even greater increase in aggregate effectiveness (Grabowski, 2006). On a per capita basis, given that nursing home costs include room and board, it is not surprising that nursing home care is more expensive than its HCBS alternative (Grabowski, 2006). Research has compared projected and actual Medicaid long term care cost over time in the U.S. states of Colorado, Oregon, and Washington (Alecxi et al, 1996). These states were chosen because HCBS accounted for a significant proportion of total Medicaid long term care recipients (Grabowski, 2006). Using the most conservative model assumptions, HCBS waiver spending generated \$33.8 million in savings in Colorado in 1994, \$27.8 million in savings in Oregon in 1993 and \$49 million in 1994, and \$57.1 million in savings in Washington in 1994 (Grabowski, 2006).

2.5 The Role of Assessment

2.5.1 Background to interRAI

InterRAI is a collaborative network of researchers from over 30 countries committed to improving health care for persons who are elderly, frail, or disabled (interRAI, 2009). The goal of interRAI is to promote evidence based clinical practice and policy decisions through the collection and interpretation of high quality data about the characteristics and outcomes of persons served across a variety of health and social services settings

(interRAI, 2009). The non profit organization known as interRAI, International Resident Assessment Instrument, was formed by researchers across the globe in 1992 to promote the use of validated assessment instruments and for international comparisons of data (Fries and Fahey, 2003). The origins of interRAI though began in the United States in 1987 as a clinical assessment tool and a foundation for improving the health care of the elderly and frail in nursing homes (Fries and Fahey, 2003). Over fifteen years later, the interRAI tool is currently in place in one form or another in 30 countries such as: Australia, Canada, Czech Republic, Finland, France, Denmark, Germany, Hong Kong, Iceland, Israel, Italy, Japan, the Netherlands, New Zealand, Norway, South Korea, Spain, Sweden, Switzerland, Taiwan, the United Kingdom, and of course the United States (Fries and Fahey, 2003).

Each country has tailored the multi-faceted system of interRAI to fit within their societal, cultural and health care community needs. An important initial aspect in the development of interRAI was noted to be the need for uniform and accurate collection of data from within and across service sectors, and subsequently across international lines (Fries and Fahey, 2003). With this data, researchers could look across many different aspects of care in nursing homes, perform cross comparisons within the nursing home communities, and affect positive lifestyle changes for our rapidly expanding community of elderly (Fries and Fahey, 2003). The interRAI tool, which as noted was initially put into place as a clinical assessment tool for use in nursing homes, has now expanded and has fifteen instruments. Those instruments are the original Long Term Care Facility version, Community Health Assessment, Contact Assessment, Assisted Living version, Home Care, Acute Care, Post Acute Care, Mental Health, Community Mental Health, Emergency Screener for Psychiatry, Palliative Care, Persons with Disabilities, Wellness, Quality of Life, and Intellectual Disability.

Although each instrument in the interRAI family of tools and applications has been developed for a particular population, they are designed to work together to form an integrated health information system (interRAI, 2009). InterRAI instruments all share a common language, that is, they refer to the same clinical concept in the same way across

instruments, use common measures that enables clinicians and providers in different care settings to improve continuity of care, as well as to integrate care/supports for each individual (interRAI, 2009). Common language also allows families, advocates and funders to track the progress of program participants across settings and over time.

Such information can yield important findings regarding what works to improve an individual's quality of life (interRAI, 2009).

There are many different applications available from interRAI currently in use for varying populations. One tool in extensive use is the interRAI – Home Care minimum data set. The Home Care assessment system, or HC, was developed to provide a common language for assessing the health status and care needs of those frail elderly and disabled individuals who are living in the community with varying levels of formal health care and/or formal/informal supportive services (interRAI, 2010). Multiple rounds of testing have been accomplished, and the original HC tool was modified and upgraded to a 2.0 version in 1999. In a study by Francesco Landi et al, the MDS – HC was verified as a comprehensive assessment tool (Landi et al, 2000). Landi et al concluded that the MDS-HC scales, ‘when performed ... using recommended protocols, provided a valid measure of function and cognitive status in frail home care patients’ (Landi et al, 2000). These findings point out the overall validity of the functional and clinical data contained in the MDS-HC assessment (Landi et al, 2000). Use of the MDS-HC gives the unique opportunity of setting up a database, a prerequisite for all epidemiological evidence based medicine studies (Landi et al, 2000). The HC system is currently being used in North America (Canada, and multiple states in the US), Europe (Italy, Switzerland, Finland, etc.), and Asia (Hong Kong, Japan) and Australia (interRAI, 2010).

Strengths of the HC assessment tool include its ability to identify and follow up issues which a frail elderly or disabled person may have in relation to their ability to remain living in the community, the ability for an assessor to compare data over multiple rounds of assessments and to share the data (referrals) if needed with other health care and/or social supportive services via a shared common language for assessment, the ability to set up a comprehensive and shared database for health care providers, and its ability to

monitor a person who may have chronic needs for care. Perhaps most important though, the MDS – HC tool is a person centred assessment rather than a fragmented site specific assessment (interRAI, 2010). The assessment itself is carried out by an interRAI assessor, preferably at the home of the participant.

2.5.2 Content and Application in New Zealand

In 2006, a successful trial of the interRAI - Home Care tool was completed in five district health boards, namely Waikato DHB, Bay of Plenty DHB, Hutt Valley DHB, Capital & Coast DHB, and Canterbury DHB, across New Zealand (Weidenbohm et al, 2008). A New Zealand review (Martin & Martin, 2003) concluded that the interRAI – HC tool appeared to be the ‘gold standard’ of assessment tools. It was reported that the interRAI-HC was an established, comprehensive well validated instrument that covered all domains (Martin & Martin, 2003). It was noted that accurate assessment would be dependent upon the competency of assessors and recommended that time and attention would be required to adequately train assessors, but that after training very good results should be obtained (Martin & Martin, 2003).

Prior to the completion of the successful trial of the MDS – HC, the CDHB through the Older Persons’ Health Specialist Service was using a handwritten form for the assessment of older people in their homes. This form was called the Support Needs Level and it was used throughout the DHB. The Support Needs Level was five pages long consisting of sections concerning the following subjects: Living Situation, Supports Networks, Leisure Activities, Communication, Household Management, Sensory Function, Mobility, Pain Management, Personal Care, Cognitive Functions, Income Support, situation or changes since initial assessment, and carer support information (CDHB, 2005). Each section gave the assessor a limited amount of space with which to hand write their assessment of the client. Obviously there is potential for wide variations in consistency from one assessment to another with hand written notation, along with other issues such as the duplication and/or omission of information, the possibility of poor writing skills, lost or misplaced forms, and the increased amount of time needed to complete the form and to

share information between various health or social care providers. Concerning current client medications, the Support Needs Level had only two lines available to the assessor, and several other sections were inadequate in the depth and scope of questioning.

In April of 2008 the New Zealand Ministry of Health allocated funds for the implementation of a four year rollout of the Home Care tool across all DHB in New Zealand (Gilhooley, 2008). The interRAI – HC assessment tool is being rolled out and utilized by the DHB due to previously acknowledged issues around the assessment of older people in New Zealand (Gilhooley, 2008). These issues include the inter-relationship between health and disability, duplication and omissions in assessments, lack of consistency across settings, disciplines and regions, etc (Gilhooley, 2008). It was due largely to issues such as these that the New Zealand Guidelines Group (NZGG) recommended the interRAI – HC to the MoH in order to assess the needs of the elderly, and to be used throughout the DHBs. It was only after this recommendation was made that the MoH instigated the pilot project of the interRAI – HC tool in the five aforementioned DHBs. Upon the successful completion of the pilot program, the MoH then committed to invest in interRAI across the DHB.

Some of the early implementation experiences of assessors during the pilot program in the five listed DHBs included:

- *The HC module was viewed by assessors as a thorough and comprehensive clinical assessment instrument best suited to people with complex needs not those with lower needs*
- *Clinical Assessment Protocols (CAP) were viewed as a valuable addition, however in some instances assessors found CAPs to be under or over sensitive to triggers in some instances. Assessors implied that each CAP must be reviewed to ensure that it has been appropriately triggered.*
- *The main challenge experienced by assessors during the trial was technical difficulties with the software. This often resulted in double entries with the assessment data, consequently increasing the time with completing the assessment (Weidenbohm et al, 2008).*

CAPs are triggered areas of need embedded into each MDS assessment which are based upon the assessment findings (Weidenbohm et al, 2008). Each CAP has a written guideline that provides further information about the triggered problem area (Weidenbohm et al, 2008). More specifically, the guidelines describe the background of the problem, further assessment that may be needed and possible intervention strategies (Weidenbohm et al, 2008).

With regard to the implementation of interRAI – HC in the Canterbury DHB, there were some challenges in the initial implementation. Those challenges revolved around the roles of assessors, the time needed to complete the assessments, the support which the assessors required and the need for further training, the frustration of slow computer software, and the fact that some community providers were dissatisfied with the initial referral reports (Gilhooley, 2008). These early issues were overcome through engagement and consultations with providers, continued staff training, adequate resourcing, and peer support (Gilhooley, 2008).

The next stage of interRAI in New Zealand, both locally and at the national level, is the roll-out of the MDS - HC assessment throughout the country. At the local level, implementation will see an increase in the use of the Contact Assessment (CA).

The interRAI Contact Assessment (interRAI CA) supports the intake process for agencies providing home care and/or palliative care. Its design was guided by three goals:

- *To support decision-making about the urgency for immediate service provision*
- *To record essential clinical information on persons who would not be receiving comprehensive assessment at a later stage*
- *To provide the minimum clinical information to enable short-term services to be put in place before completion of a full interRAI assessment (interRAI CA, 2010).*

The CA is not a substitute for a comprehensive interRAI assessment as it records only essential information needed at the time of intake to support decisions regarding the need for further in-depth assessment, the urgency for home care service provision, and the need for specialised services (interRAI CA, 2010). The CA is not intended to be a care planning instrument like the interRAI - HC, but it does provide some important clinical

information needed at the onset of home care service provision (interRAI CA, 2010). At the local and national levels, full implementation of the HC assessment will also see to an improved quality monitoring program due to the nature of interRAI's integrated health information system (Gilhooley, 2008).

Important benefits of the implementation of interRAI throughout New Zealand are: the investment in the workforce (interRAI training provides opportunities for professional growth for those involved in its implementation and assessment), robust decision support mechanisms and pathways, and the potential for research activities (Gilhooley, 2008).

There are comparisons between the implementation experience of the Arizona Long Term Care System and that of the MDS – HC in New Zealand. Through the ALTCS, eligible applicants are assessed via a pre-admission process which begins with a functional assessment of an individuals' activity of daily living abilities, psychosocial functioning, continence, sensory impairment, and a medical section which includes medication and monitoring needs, catheter and ostomy care, rehabilitation nursing needs, and overall care for medical problems (Weissert et al, 1997). The elderly living at home in New Zealand are now assessed via the interRAI – Home Care MDS-HC through the DHB. The MDS-HC has over a dozen different sections ranging from Cognitive Patterns and Informal Support Services, to Physical Functioning, Continence in Last 7 Days, and Disease Diagnosis. Through the ALTCS, assessors themselves are selected based upon appropriate background and experience, and receive extensive initial training and retraining through in-servicing. This process is very similar to the one in place to employ and train interRAI – Home Care assessors through the DHBs, where 71% of initial assessors employed were Registered Nurses (Weidenbohm et al, 2008), and of whom receive extensive initial and follow up training. Home care services provided through the ALTCS include case management services, hospice care, home delivery of meals, various home health agency services, homemaker services, personal care services, respite care services, attendant care, environmental modifications and other needed care in a home for adults (Weissert et al, 1997). The DHBs in New Zealand, upon analyzing results from the MDS-HC assessment, refer recognized needs of those assessed elderly living in their own

homes to similar social and health care agencies to aid in supporting those same elderly to remain living in their own home(s). Research has shown that the ability to remain living in one's own home, as opposed to the alternative of being forced to move into a retirement home, can affect a person's own self-assessed and perceived quality of life.

2.5.3 Limitations of interRAI

Although the interRAI – Home Care module has been rated as most thorough and comprehensive by its assessors, it does have its limitations. In 2008, Dr. John Morris, an interRAI fellow and researcher from Hebrew Senior Life and Harvard University, spoke at an interRAI conference in Barcelona, Spain, about the initial moves to create a Quality of Life survey through the interRAI system (interRAI.org, 2008). This was in response to the major limitation of the dearth of self assessment tools within interRAI. A subjective approach to quality of life signals that people themselves are the best appraisers of the 'value or worth' of their own lives (Hambleton, Keeling & McKenzie, 2009). The MDS - HC assessment does have sections in which the assessor covers topics ranging from communication and hearing patterns, mood and behaviour patterns, and social functioning, all factors reflected in person's own quality of life, but there is no section which specifically deals with the topic of quality of life itself, and certainly no self assessed section for QoL. In the paper 'Evaluation, not description, of quality of life by global self-assessment', Bernheim et al describe the importance of self assessment in quality of life, and laments the option of an observer weighed QoL questionnaire in which there is no self input by the person him or herself. According to Bernheim, since the items and dimensions on many quality of life questionnaires are observer selected and un-weighted, overall scores do not reflect the actual quality of life of individuals (Bernheim et al, 1995).

2.5.4 An Alternative Approach

More and more, research is finding that what is needed to complete a holistic and well rounded approach to elder care is a self assessed quality of life survey to go along with

the interRAI – Home Care assessment. More and more health care professionals are espousing the importance of self assessment when it comes to quality of life. Indeed, central to the process of holistic care is the importance of the individual's perspective, views, and self assessment (Strahan et al, 2005), especially when it comes to quality of life. The idea of self assessment practices was central to the HATCH promotion in Rhode Island. HATCH (Holistic Approach to Transformational Change), instituted the individualised care organisational self assessment survey for those elderly who live in nursing homes. The survey itself is a three page self assessed questionnaire which residents fill out regarding issues such as choice, daily schedules, routines, etc. versus the amount of discussion and power which the residents have in relation to decision making (Individualized Care, 2007). The main reason behind the development of this new self assessment tool was to ensure a more resident centred orientation of care in Rhode Island nursing homes (Rhode Island Dept. of Health, 2010).

Part of the power of self assessment is the idea of person centred care. The Department of Health in North West London has this to say about person centred care:

Person Centred Care means listening to people to find out what is most important to them. Assumptions are not made. Care is holistic and centres on the whole person: who they are, their life before, and how they currently feel (Dept. of Health, 2010).

Concerning the importance of self assessment, a project from North West London states that a holistic assessment should take place in partnership with the individual and their carer(s) and should be proportionate; covering all the needs of the individual, not just the physical or medical, but also their spiritual, emotional, and social needs. Self assessment should be encouraged (NW London Stat Health Authority, 2010). More and more there are health organisations, researchers and people themselves who recognise the important place that self assessment holds in the quality of life of the elderly. It is through the work of Dr. John Morris that interRAI has recognised and taken the first steps forward in regards to adding the self assessed quality of life survey to the interRAI family of tools.

A recent study into the wellbeing of the elderly surveyed 1680 people aged 65 to 84 (Koopman-Boyden & Waldegrave, 2009). It found that, although 88 per cent were “satisfied” or “very satisfied” with their lives, their wellbeing was largely dependent on factors such as home ownership (Koopman-Boyden & Waldegrave 2009). The study’s definition of wellbeing involves people both experiencing a sense of satisfaction with life, and acquiring appropriate capabilities to achieve a good quality of life (Koopman-Boyden & Waldegrave, 2009). The report collected subjective and objective data across the following domains: leisure and recreation, health, education, living arrangements, work and retirement, safety, economic and standard of living, social connectedness, rights and entitlements and finally, culture and religion (Koopman-Boyden & Waldegrave, 2009). The new interRAI QoL survey covers similar issues within its domains. A main focus of Koopman-Boyden and Waldegrave’s study was the wellbeing of the 65 to 84 age population in New Zealand (2009). The report studied the level and the determinants of that wellbeing, as well as possible ways of improving the wellbeing of older people, through providing robust evidence from a substantial national random sample of older New Zealanders (Koopman-Boyden & Waldegrave, 2009). The report concluded, amongst other findings, that policy at the government and community level should ensure that older people, regardless of gender, have well resourced home based services (Koopman-Boyden & Waldegrave, 2009).

Currently in New Zealand there is no uniform method of measuring the wellbeing, or quality of life, of the elderly. The results published by Koopman-Boyden and Waldegrave (2009) indicate, among other things, that both home ownership, and the presence of well resourced home based services, ie HCBS, are key pieces to wellbeing, or quality of life. HCBS services in New Zealand are presently provided through early referrals from the interRAI – HC assessment, and through physician referral. Prior to interRAI, home care needs were provided through an assessment of needs by an assessor from a District Health Board. The assessment, called a Support Needs Assessment, was carried out through a pen and paper approach, and there was limited coordination or standards throughout assessment teams across DHBs. The lack of a legitimately integrated health information system to store, codify and share the collected information presented a

vacuum which the interRAI – HC tool has filled. The interRAI – HC MDS is in place to assess the health needs of the elderly through referrals for needed care or services, and ensures that needed HCBS services are provided. The HC assessment was originally intended to focus on the person’s functioning and quality of life by assessing needs, strengths, and preferences (interRAI.org, 2010). What is needed now in New Zealand is a Quality of Life self assessment tool for our elderly living at home. This tool should be used uniformly throughout the DHB and, optimally, in conjunction with the MDS – HC tool.

3.0 **MEASURING AND APPLYING QUALITY OF LIFE INDICATORS**

3.1 Quality of Life Indicators

Hambleton, Keeling & McKenzie described the litany of QoL literature as a jungle: vast, dense and difficult to penetrate, especially for those entering into the field without a specialist QoL background (2009). Felce and Perry describe broad social indicators of QoL as having been used to chart the wellbeing of populations at the aggregate level, and social and psychological indicators as having been developed to reflect individual welfare (1995). As operational definitions of QoL are diverse, with variability fuelled not only by use of societal and/or individualistic perspectives, but also by the range of applicable theoretical models or academic orientations (Felce & Perry, 1995), such is the difficulty with measuring and applying QoL indicators. In recent decades, scientists have offered several alternative approaches to defining and measuring quality of life with social indicators such as health and levels of crime, subjective well being measures (assessing people's evaluative reactions to their lives and societies), and economic indices (Diener & Suh, 1997). In New Zealand, the Quality of Life report, published by the Quality of Life Project, provides a comprehensive assessment of quality of life in 12 New Zealand cities (Quality of Life Project, 2010). The purpose of the QoL report is to provide information that contributes to the understanding of social, economic and environmental conditions which can be used to describe and quantify the quality of life of those living in New Zealand's major urban areas (Quality of Life Project, 2010). The report includes 68 key quality of life indicators (encompassing 186 individual measures) across 11 domain areas (Quality of Life Project, 2010). The data for these indicators and measures has been drawn from two main sources:

- *Quality of Life surveys: these biennial surveys are conducted in partnership with the Ministry of Social Development and measure resident perceptions of health and wellbeing, their community, crime and safety, education and work, the environment, culture and identity*

- *Secondary data sources (e.g. from government agencies and non-governmental organisations) (Quality of Life Project, 2010).*

The eleven domain areas for the indicators of QoL include:

- *People*
- *Knowledge and Skills*
- *Economic Standard of Living*
- *Economic Development*
- *Housing*
- *Health*
- *Natural Environment*
- *Built Environment*
- *Safety*
- *Social Connectedness*
- *Civil and Political Rights (Quality of Life Project, 2010)*

Each domain area contains between four to eleven individual measures of QoL indicators. The report contains an extensive overview of QoL indicators which affect New Zealanders every day.

Important in the definition of an indicator of QoL is the need to clarify between four differing options: Objective indicators, subjective indicators, causal indicators and effect indicators. Objective indicators of QoL are treated as empirical, observable entities that can be readily counted, measured or compared: rates of employment, income, marital status, home ownership, hospitalisation and mortality rates, representing what is described as the ‘material level of living’ (Hambleton, Keeling & McKenzie, 2009). On the other hand, Subjective indicators of QoL signal that people themselves are the best appraisers of the value or worth of their own lives (Hambleton, Keeling & McKenzie, 2009). Common indicators sought in this approach include psychological responses, personal feelings, attitudes, preferences, judgments, life or job satisfaction, happiness or the perceived benefits of a particular program (Hambleton, Keeling & McKenzie, 2009). Some indicators are of a causal and/or effect nature. Fayers, Hand, Bjordal and

Groenvold well described these two important QoL indicators in their report ‘Causal Indicators in Quality of Life Research’:

If a patient suffers from symptoms or side-effects, we may infer that their QoL must, as a consequence, be poor. Thus, if a patient reports high levels of even a single severe symptom we would expect their QoL to be poor. However, the converse need not apply. Their poor QoL could be a consequence of other factors. Therefore it appears reasonable to assume that symptoms ‘cause’ deterioration in the QoL and that they are causal items. If a patient has a poor QoL as a result of disease or illness, they are likely to be depressed or anxious. These items can serve as indications that a patient has a poor QoL. Such items are called effect indicators. (Fayers, Hand, Bjordal & Groenvold, 1997)

These two types of items, effect indicators and causal indicators, have fundamentally different relationships within QoL, however, the need to distinguish them explicitly has been poorly recognized in the past (Fayers et al, 1997). Quality of Life indicators indeed make up an important aspect in the determination of QoL itself.

3.2 Quality of Life Assessments

Mary James of the Institute of Gerontology at the University of Michigan has long been a proponent of data driven long term care policy (Institute of Gerontology, 2010). Her work on the Participant Outcomes and Status Measures for Home and Community Based Services (POSM HCBS) has enabled a more efficient Quality of Life Assessment due to its important quality of the self assessment of participants in Michigan. Few QoL assessment tools in use today hold the all important quality of self assessment. Self Assessment tools for the determination of QoL are important due to inherent differences between people themselves. The Participant Outcomes and Status Measures for Nursing Facility, also known as POSM NF (James, 2010), is used as an assessment tool to assess QoL amongst nursing facility residents in Michigan. POSM NF built upon the initial success of the POSM HCBS, which was designed to assess the QoL of participants who were still living in the community. POSM NF was deemed to be an attractive option due to many different considerations. First, POSM HCBS had been designed with extensive

stakeholder input, had undergone multiple rounds of testing, and was in routine use throughout the state of Michigan (James, 2010). Second, like its community counterpart, the resultant POSM NF is a brief instrument that focuses only on domains not already measured by the interRAI – Long Term Care Facility, which is federally mandated in the United States and in use in all nursing facilities (James, 2010). Third, computerisation of the tool allowed that the data could be easily categorised, analysed, and, if needed, shared with other health professionals (James, 2010). Finally, use of the POSM NF enabled the data to be compared and used as part of the international effort by interRAI to create a standardized subjective QoL instrument that could support cross-national comparisons (James, 2010).

The self assessed POSM Quality of Life Assessment has ten different domains ranging from ‘Availability of Paid Care/Supports’, ‘Relationship with Support Workers’, and ‘Community Integration’, to ‘Personal Relationships’, ‘Autonomy’, and ‘Dignity/Respect’, amongst others (POSM, 2006). Each domain has up to ten questions of which there are up to eight responses to choose from. The responses range from ‘Not applicable’ and ‘Refused to Answer’, to ‘Strongly Disagree’, ‘Not Sure’, and ‘Strongly Agree’ (POSM, 2006). The domains and questions in POSM are very similar to those in the interRAI QoL survey and thus the POSM NF data can be used in interRAI analysis (James, 2010).

Another quality of life tool in use today is the Health Related Quality of Life Index. Health related QoL measures are used to assess care and treatment in terms of a ‘life worth living’ (Hambleton, Keeling & McKenzie, 2009). This assessment takes place predominantly within a positivist paradigm where the valuation of care, treatment and life circumstances is undertaken with the idea that it is possible to quantify the quality of a human life (Hambleton, Keeling & McKenzie, 2009). One prominent Health Related QoL tool in wide use today is the Multi-Attribute Health Status Classification System: Health Utility Index – 3 (HUI3). Health Utilities Inc, the parent organisation behind HUI3, specialises in preference-based (utility) measures of health-related quality of life for use in describing treatment processes and outcomes in clinical studies, economic

evaluations of health care programs, and the measurement and monitoring of population health (Health Utilities, 2010). HUI is a family of generic health profiles and preference-based systems for the purposes of measuring health status, reporting health related quality of life, and producing utility scores to describe health status (Horsman, Furlong, Feeny, & Torrance, 2003). The HUI3 survey can be self or interviewer administered (Health Utilities, 2010). The HUI3 measurement system is a generic, preference scored system for measuring health status and health related quality of life, and produces scores for comparison (Health Utilities, 2010).

HUI3 is a prominent measure of health-related quality of life widely used in population health surveys, clinical studies and cost-utility analyses (Asakawa & Feeny, 2006). HUI3 has 8 domains (vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain), with 5 or 6 responses for each attribute, and has been used to assess health status in a number of chronic conditions (Asakawa & Feeny, 2006). HUI3 has been shown though to be an effective overall tool. It has been able to discriminate various aspects of burden associated with common ailments of the elderly, is able to describe differences in overall Health Related QoL levels, and is useful in assessing the Health Related Quality of Life for those elderly living in the community and in institutions (Asakawa & Feeny, 2006).

Few qualitative studies though have studied quality of life issues for the elderly who live in their own homes in New Zealand; however, QoL has been most extensively measured in quantitative terms (Hambleton, Keeling & McKenzie, 2009). Historically, the perspectives of older people are rarely explored in measures to evaluate what QoL might mean to elders (Hambleton, Keeling & McKenzie, 2009).

3.3 InterRAI Quality of Life Self Assessment

The interRAI QoL self assessment survey is a tool used to measure the subjective well-being of an elderly person who is living in their own home. Subjective well-being research is concerned with individuals' subjective experience of their lives (Diener & Suh, 1997). The underlying assumption is that well being can be defined by people's

conscious experiences in terms of hedonic feelings or cognitive satisfactions (Diener & Suh, 1997). The field is built upon the presumption that to understand individual experiential quality of life, it is appropriate to directly examine how a person feels about life in the context of his or her own standards (Diener & Suh, 1997).

Recent research by Dr. John Morris of Harvard University and Hebrew Senior Life has shown promise that a Quality of Life self assessment would enable for a more comprehensive and holistic assessment of the needs and requirements of elders living in their own home (interRAI, 2008). Concerning the launch of pilot studies of the proposed new QoL assessment, interRAI.org released the following statement:

interRAI researchers have recently made important first steps toward developing a new dimension to its assessment systems, focused on the persons' own perspective of their life and care experiences. Existing interRAI assessment instruments are based on the assessors' evaluation of the person's problems, performance and perceptions. The proposed new assessment instrument will focus on the persons' own perception of their quality of life, in the context of the care setting in which they live.

The assessment will initially be best suited to persons receiving home care or living in long term care settings. The assessment will complement and directly link to the conventional interRAI assessment systems such as the interRAI Home Care and interRAI Long Term Care Facility (interRAI.org, 2008).

Currently, interRAI assessors around the world gather information about clients from minimum data set assessments which enable health care professionals to formulate an evaluation of the client's needs through observation, performance and assessment (interRAI, 2009). Although this has been shown to be a successful method of gathering and disseminating needed information, it only provides for the perspective of the interRAI assessor. Through the use of the QoL Assessment, we can ensure that the voice of the assessed person is heard through self assessment. The assessment is not a generic QoL tool as such; rather it explores the quality of life of clients who are receiving formal services (interRAI QoL Research, 2010).

The idea of self assessment has roots in health care research. Studies have shown that there is a correlation between self ratings of health and predictors of mortality. In 1982, Mossey and Shapiro showed that elderly Canadians' self ratings of health were better predictors of seven year survival than their medical records (Idler & Benyamini, 1997). The concept of health related QoL (HRQL) was outlined in 1999 (Wood-Dauphinee, 1999). HRQL is a controversial topic that has been widely discussed and the focus of much development in recent years (Wood-Dauphinee, 1999). Social scientists, economists, clinical researchers, the pharmaceutical industry and, to a lesser extent, clinicians have engaged in lively debate about its meaning, its measurement, and its usefulness as an outcome of health care (Wood-Dauphinee, 1999). Today most would agree that HRQL instruments can supplement information from traditional measures of clinical endpoints and provide a clearer picture of the outcomes of care by taking patients' points of view into account (Wood-Dauphinee, 1999). The idea of who should measure QoL, medical doctors or the patients, was examined in a study published by the British Journal of Cancer in 1988. Slevin et al theorized about the extent to which a doctor or health professional could make a valid assessment of a patient's quality of life, anxiety and depression (1988). This was investigated in a series of cancer patients.

Doctors and patients filled out the same forms at the same time. Correlations between the two sets of scores were poor, suggesting that the doctors could not accurately determine what the patients felt. A further study examining the reproducibility of these scales demonstrated considerable variability in results between different doctors. It was concluded that if a reliable and consistent method of measuring quality of life in cancer patients is required, it must come from the patients themselves and not from their doctors and nurses (Slevin et al, 1988).

Quality of life measures are increasingly used to supplement objective clinical or biological measures of disease to assess the quality of service, the need for health care, the effectiveness of interventions, and in cost utility analyses (Carr & Higginson, 2001). Their use reflects a growing appreciation of the importance of how the elderly feel and how satisfied they are about the many and varying aspects of QoL (Carr & Higginson, 2001). In this respect, quality of life measures capture patients' perspectives of their

disease and treatment, their perceived need for health care, and their preferences for treatment and outcomes (Carr & Higginson, 2001). QoL measures are often hailed as being patient centred, but the challenge in measuring quality of life lies in its uniqueness to individuals (Carr & Higginson, 2001). Indeed, in order to achieve and maintain a truly person centred QoL assessment, it is important that it be self assessed.

The interRAI QoL survey used in this study is intended for those elderly living in their own homes. It is used in conjunction with the interRAI – HC module in order to reveal a holistic account of the needs of the elderly. The subjective nature of quality of life differs from person to person and requires that the interRAI QoL survey be completed either via the client directly or through an interview.

The QoL self assessment survey contains nine different sections:

- Privacy
- Food/Meals
- Safety/Security
- Comfort and Environment
- Autonomy
- Respect
- Worker Responsiveness
- Activities and Community Integration
- Personal Relationships

Each section contains between four to seven questions and can either be filled out directly by the person, or via the assessor reading out the questions and answers to the person.

Certainly the use of the interRAI quality of life survey is not simply about gathering data and status reports, but is intended for use as a starting point for intervention to improve the quality of life of the participants. The data gathered from the QoL surveys can be used to both highlight the positive and negative affects of the lives of the elderly living in their own homes. Follow-up with the negative aspects of the QoL surveys, at both the individual and group summary levels, will allow for immediate insight and intervention

necessary by health care professionals and other relevant social organisations. Further study into the positive aspects of the QoL survey at an aggregate level could allow for a baseline to be developed to guide and comprehend future QoL data. Both quantitative and qualitative data can be provided from describing the status of client need from both the MDS and from the QoL responses. It is possible that results could then be analyzed by comparing two sets of data from the MDS and the QoL, such as the relationship of medical fragility to the QoL score(s).

Many questions remain regarding the implications of the use of the QoL survey on the subset of the elderly living in their own homes with formal support. Studies by Hughes et al (1991), Weissert et al (1997), and Grabowski (2006) all have shown that an investment in home based care can be a wise financial move for a health care sector that needs to carefully watch its budget. With the interRAI – HC module now in place in the DHB, home based needs such as physiotherapy; meals on wheels, home help, etc. are identified and coordinated. By implementing the QoL Survey as a follow-up to the MDS – HC, QoL issues can be similarly identified and coordinated. This would presumably result in more elderly living by choice in their own home, with needed supports, and with attention to their quality of life issues and needs.

4.0 Research Methods

4.1 Research Purpose

The purpose of this research is to validate the interRAI Quality of Life Survey as a tool for use in New Zealand amongst those elderly living in their own home who have been previously assessed by the MDS – HC tool and are receiving some sort of publicly funded health care, social or community support.

The Quality of Life survey reported in this thesis is undertaken for several reasons. First, there is a dearth of self reported Quality of Life tools available for use in the elderly population in New Zealand, particularly for those elderly who are living in their own homes with public support. A second and very important reason is to give the elderly a greater voice in reporting their own quality of life and in considering options available to them. Thirdly, by linking QoL to the interRAI project, this will aid interRAI to develop an extended and integrated system of assessment. It is hoped that this will assist elderly people more effectively deal with their QoL through greater organisation, efficiency, and communication amongst the DHB and other service providers.

Furthermore, the research intends to present an overview of the pressures which the ageing New Zealand population places upon public policy. The quality of life of older people will be compared via the interRAI QoL survey, and consideration will be given to how best to apply quality of life measures alongside the interRAI – HC tool here in New Zealand.

4.2 Research Protocol

The research itself focused on the QoL of thirty participants. Each participant was first assessed through an interRAI – HC assessment in their own home by an assessor from the CDHB. Upon completion of the assessment, they were given the option of being contacted by the researcher about participation in the interRAI QoL Survey. Contact by

the researcher by telephone ensued, which was then followed up by a face to face information session at the home of the participant. At this time, thirty out of thirty one potential participants decided to sign the informed consent form for participation. As the QoL Survey itself is self reported, each participant was free to read through the survey and answer for themselves questions regarding their thoughts about their own quality of life.

Approval for this study was granted by the Southern Region Health Ethics Committee (HEC 2009/46) in accordance with the Ministry of Health and the Health Research Council of New Zealand procedures. The application included approval from the Health Sciences Centre University of Canterbury, and the Canterbury District Health Board. In addition, approval was received from Age Concern Canterbury to refer any QoL issues which arose during discussion(s) with survey participants.

Each participant signed two consent forms. The first (Appendix A) gave permission for the interRAI assessor to pass along the participant's telephone number to the QoL researcher. The second (Appendix B), agreeing to be a part of the study, was signed after the participant had read through an information sheet (Appendix C) which explained the QoL survey study.

The study involved the co-operation of the Canterbury District Health Board and Age Concern Canterbury. Permission for use of resources and/or for referral was obtained and coordinated with the CDHB interRAI Manager, Older Person's Health Service, and Age Concern Community Health Officer.

4.2.1 Ethical Issues

When looking further into the ethical considerations of the QoL Survey, it is important to note the fact that the participants are in a particularly vulnerable group. It is therefore important to fully establish the thoughts behind the ethics of the study. Codified principles, such as those promulgated by the U.S. Department of Health and Human

Services (Title 45, Part 46 of the Code of Federal Regulations), as well as those developed for specific fields of study such as the APA's Ethical Principles of Psychologist and Code of Conduct (2002) are intended to ensure that researchers consider all potential risks and ethical conflicts when designing and conducting research (Marczyk, DeMatteo & Festinger, 2005). Moreover, these principals are intended to protect research participants from harm (Sieber & Stanley, 1988).

Other ethical considerations involved in the QoL Study were Privacy and Confidentiality, Benefits and Risks involved, and withdrawals from the study.

(1) Privacy and Confidentiality - Only the researcher and project supervisors had access to the data gathered from the QoL Survey and/or MDS – HC assessment. Once each QoL survey was completed, data entered into the Excel spreadsheet using only a coded number to indicate the participant's personal data. At no time was any personally identifiable data reproduced and none will be published in the future. The collected surveys were stored within the researcher's locked office. Data were stored on the researcher's password-protected personal computer. After completion of the study, data will be stored securely for 10 years at the Health Sciences Centre, University of Canterbury. As this is a quality of life study, particular participant issues sometimes arose during the interview with implications for a participant's current quality of life. In each case, the participant was spoken to about Age Concern Canterbury, given an information pamphlet, and urged to call them for help in addressing their QoL issue.

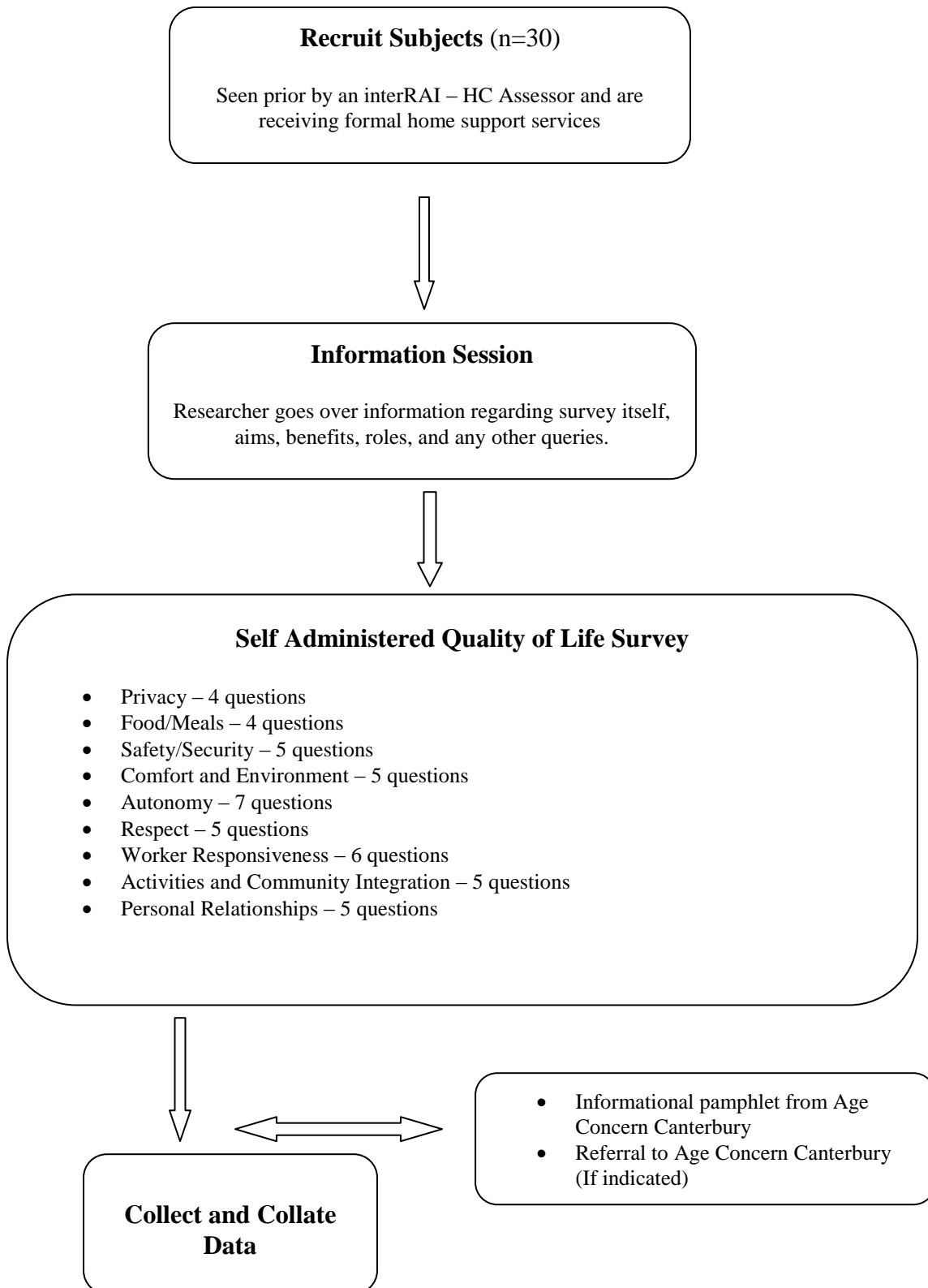
(2) Benefits and Risks – Both the possible benefits and the risks involved in participating in the study were discussed with all prospective participants. Each participant had an opportunity to benefit from feedback regarding the collected data from the survey. Feedback was made available to participants as requested. In addition, a brief summary of the study results will be posted to each person when the project is completed if requested and the option ticked on the informed consent form. An additional, albeit broad, benefit was that recommendations were to be made in the completed thesis which would assist future participants with their own quality of life. It was expected that there would

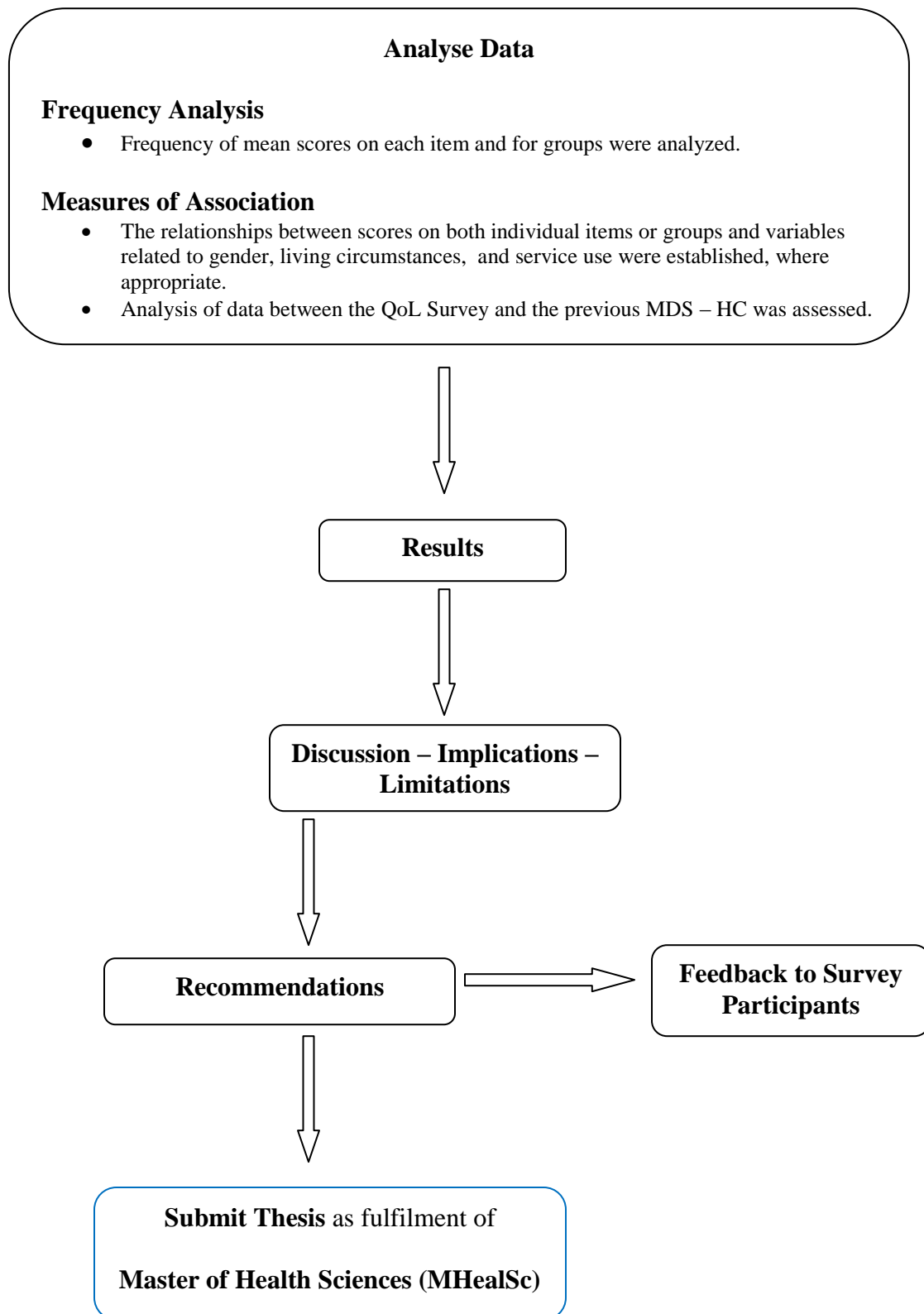
be no risks associated with participation, however, if the completion of the survey raised issues or anxieties which a participant would like to discuss, referral contact numbers were made available for the interviewers' supervisors and/or for Age Concern Canterbury. Through the informed consent, participant approval was given for data from this study to be used in future related studies, once approval has been received from a Health & Disability Ethics Committee. Participants were informed that said future related studies had not yet been given any approval from the Health and Disability Ethics Committee.

(3) Withdrawals from study or decision not to participate – Participants were informed that at any time they could decide not to participate, or to withdraw from the study. They were made aware that there would be no adverse effects from such a decision, and also that there would be no changes to any current services they were receiving due to any withdraw or refusal to participate. Also, any withdraw from the study would result in any gathered information from the study also being withdrawn.

4.3 Study Design: Self Assessed Survey Study

A self assessed QoL survey (Appendix D) was administered to study participants. The survey was completed either by the participant themselves, or via the researcher reading the questions and possible answers aloud and marking answers chosen by the participant. The survey itself is a trial version of the interRAI QoL survey assessment in use internationally, but adapted for local conditions here in the metropolitan Christchurch area (by the researcher only), and measures QoL across nine different categories. These adaptations were minor, and included changing the date to a DD/MM/YYYY format, and changing the spelling of program to programme. Also, the sentence “On behalf of interRAI, I wish to thank you for your participation.” was added to the last page, along with a section entitled “For interRAI interviewer”, which had a large blank section for personal notes and observations for the interviewer. Adaptations made to the survey did not include any change in survey statements or sections. Quantitative and qualitative analysis was performed on collected data. Figure 4.1 outlines the research process diagrammatically.

Figure 4.1 Study design flow-chart – interRAI QoL Survey



4.4 Subjects

4.4.1 General Recruitment Process

Recruitment for the QoL Survey came directly through the Canterbury DHB, specifically from the Older Person's Health Service interRAI team at Princess Margaret Hospital. The interRAI Manager from the Older Person's Health Service was briefed concerning the QoL Survey, its origins in interRAI, and its expectations. It was agreed that recruitment of potential participants for the QoL survey would come from the pool of those who had been seen by a CDHB interRAI – Home Care assessor within the previous six weeks. Also, from that group, it was necessary that the Cognitive Performance Scale score from Section B. of the MDS – HC was less than or equal to a score of 2. A score of 0 equals a fully intact cognition; a score of 2 equals mild impairment of cognition, while a score of 6 equals a very severe level of impairment (Morris et al, 1994). The CPS provides a functional view of cognitive performance, using readily available MDS data (Morris et al, 1994). It is a useful tool for clinicians and investigators using the MDS to determine a person's cognitive abilities (Morris et al, 1994), and their capacity to respond to the QoL survey.

Patients are referred to the Older Person's Health Service via their own general practitioners or other community based health professionals after being assessed as possibly in need of assistance to remain living in their own home. The Older Person's Health Service provides MDS – HC assessment via its staff of interRAI assessors. The MDS – HC full assessment assesses the needs, strengths and preferences of the participant, facilitates referrals when needed, and provides the basis for an outcome based assessment of the person's response to care or services (interrai.org, 2010). The MDS – HC full assessment has twenty one different sections which examine a range of subjects such as Cognitive Patterns (Section B), Vision Patterns (Section D), Informal Support Services (Section G), Disease Diagnosis (Section J) and more (MDS-HC Form, 2001).

4.4.2 Summary of Inclusion Criteria

On the basis of the discussion above, the criteria for inclusion in the study population can be summarised as follows:

1. People had to be living in their own homes.
2. Publicly funded health care, social or community support such as meals on wheels, personal care, etc, was being provided to the person at their home.
3. The recruitment of the participants came solely through the CDHB as the only organization in Canterbury performing the full MDS – HC assessment.
4. From the elderly who had taken part in the MDS – HC assessment, only those who had been seen within the six weeks prior to the QoL assessment were included. This was due to several factors, amongst them consent issues, time constraints, and the desire to perform the QoL survey as soon as possible following a MDS – HC.
5. The criterion for the score of two or less on the cognitive score of the MDS – HC was decided upon due to concerns that a higher score would impair an individual's ability to answer a self administered survey. It has been noted, though, that the presence of cognitive impairment or limited understanding does not automatically disqualify a person from consenting to research studies (Marczyk et al, 2005).

4.4.3 Recruitment Pool

During the recruitment phase (June to December 2009) a written introduction to the study (Appendix A) was presented to potential participants by the CDHB interRAI assessor following the MDS – HC assessment. At that time, people had the option of ticking a box which gave the researcher permission to contact them via telephone, or they could tick a second box indicating that they were not interested in participation in the QoL survey and

did not wish to be contacted. Thirty nine people agreed to this contact. Seven others did not want the researcher to make contact with them regarding the QoL survey. In total, forty six people responded to the initial query by the CDHB assessors regarding contact by the QoL researcher. It is unknown from the recruitment phase how many participants of the MDS – HC assessment might have allowed further contact by the QoL researcher as it appears that a majority of the MDS – HC assessors did not present this as an option. According to the CDHB, there were approximately 824 interRAI – HC assessments during the researchers recruiting period of June to December 2009. Following telephone contact from the researcher to the potential participant, a date and time were set at the person's own home for contact. Of the thirty nine people who had agreed to telephone contact, eight choose not to participate further. One person was awaiting an impending move into a rest home, two were unable to be reached by telephone, four changed their minds on the telephone, and one felt that life was too busy at the moment for time to be set aside for the survey.

Thirty one people were visited by the researcher at an agreed upon time and place. The Information Sheet for participants (Appendix C) was either read by the potential participant, or read to him/her by the researcher. Any questions regarding the QoL Survey were answered at this time. The information sheet contained details about why the study was being done, its aims, the roles of the participants, benefits and risks, etc. The information sheet also contained telephone numbers for an independent health and disability advocate if there were any concerns about the rights of participants. At this information session one person refused to participate due to anxiety over signing the informed consent form (Appendix B). In all, thirty people agreed to participate. This represented a response rate of 65% from the original number of 46. The consent form (Appendix B) was then given to each participant to read, initial and sign. The process of receiving informed consent followed principles set forth by the Belmont Report which identified informed consent as a process that is essential to the principle of respect (Marczyk, DeMatteo, & Festinger, 2005).

The interRAI Self-Reported Home Care/Community Living Quality of Life Survey (Appendix D) was then administered to those participants (n=30) who had agreed to participate.

4.5 Administering the Survey

Once informed consent was given for participation in the study, each person was administered the interRAI Self-Reported Home Care/Community Living Quality of Life Survey via a face to face interview/meeting. The method of meeting face to face was chosen for reasons such as: respect for the participant, effective communication due to better ability to speak with those elderly who may have hearing difficulties, overall ability to create a better rapport with the participant, perceived notion that people who are in their seventies and older would prefer a face to face meeting rather than an extended telephone conversation or use of the post for mailing the survey back and forth. The face to face meeting also ensures that it is the participant him/herself who is answering the questions with no input from other sources. All interviews/meetings were conducted in the home of participants on a day and time which was suitable for them. Two out of the thirty participants completed the QoL Survey on their own, while twenty eight elected to have each question and answer read out to them by the researcher. For each statement the participant had the following choices for a response: 0 = Never, 1= Rarely, 2 = Sometimes, 3 = Most of the time, 4 = Always. The participant, as another option, could choose to respond: 6 = Did not know, 7 = Refused, or 8 = No response or cannot be coded from response – in which the interviewer was to write down what the participant said. Participants were made aware that there would be no changes to their current services based upon their answers from the QoL Survey.

4.5.1 Accounting for Interviewer Bias

As researchers can often be a source of interviewer bias, care was taken to avoid this possibility. Interviewer bias refers to the potential for researchers themselves to

inadvertently influence the responses of research participants in a certain direction (Marczyk et al, 2005).

In order to account for interviewer bias careful control over research procedures was maintained. Study procedures remained constant, in an attempt to minimize unforeseen variances in the QoL research design, and all procedures were carefully standardized (Marczyk et al, 2005). The procedure(s) for recruiting potential participants was set through the use of the consent form (Appendix A), in which the CDHB interRAI assessor read a brief prewritten statement concerning the QoL study:

The Quality of Life Survey is a Masters Thesis study being performed by Christopher P. Brandt from the University of Canterbury. The survey itself is intended to be a follow-up to the interRAI Assessment which you have recently been a part of. The main idea of this survey is to gain an overall assessment of your self reported quality of life. You will be presented a series of questions ranging from Privacy, Safety, Autonomy, Personal Relationships and more. If you would like to participate, more detailed information concerning the study will be presented to you upon meeting with Mr. Brandt.

During the visit from the researcher, an information sheet (Appendix C) was used. The information sheet anticipated questions which the potential participant might have concerning the QoL survey/study, and had pre-scripted answers to these questions. The informed consent form for participation in the study (Appendix B) had a series of statements concerning the study that were to be acknowledged by each participant prior to signing the consent itself. The QoL Survey (Appendix D) was intended to be a self administered survey, either by the participant him/herself, or via the researcher reading it to the participant. Care was taken not to influence the answers by oral cues, and participants were reminded that each answer was to be their own personal thoughts and feelings toward the subject matter. Research and education concerning the impact and control of interviewer effects regarding bias was undertaken by the researcher and strategies for minimizing interviewer effects were implemented and executed. Marczyk et al (2005) note that the effects of interviewer bias can be more prevalent when one individual is acting in multiple roles within a study, as in a graduate dissertation.

Standardized procedures were set in place, inclusion criteria were developed, and care was taken to preclude any interviewer bias from impacting upon the survey and study results.

4.5.2 Questionnaire Scoring and Data Entry

Following each completed interview, the participant's QoL survey information was entered onto an Excel spreadsheet. A scoring template, specifically created by Dr. John Morris for this purpose, was used to code and enter the data. Scoring of each survey item was done individually with aggregate scores calculated for each Section. This was done as soon as possible following completion to limit any errors arising from entering data incorrectly. The completed excel data set (n=30) was used to create graphs and other statistical analysis on excel, but was also transferred to SPSS 17.0. In SPSS, initial frequency variables were generated. All initial outputs were examined by the researcher to check for anomalies.

Descriptive statistics of each section of the QoL survey itself was examined in overall detail, female vs. male, meals on wheels vs. no meals on wheels, Personal Care/No Personal Care, and home alone/not home alone. Also, the Mann-Whitney U test was used to determine p-values. The Mann-Whitney U test, a non-parametric method, was used instead of the student t-test due to the small sample size, which makes it difficult to determine whether the distribution is normal or not. This allowed for testing whether or not two independent variables come from the same distribution through the use of SPSS to determine p-values. Through the use of SPSS, an acceptable level of internal consistency within the quality of life survey was determined through a Cronbach's Alpha score of 0.748.

4.6 Data Analysis

4.6.1 Statistical Procedures

Data analysis was performed on data using both descriptive and inferential statistics. In analysing the data, a variety of statistical measurements and methods were utilized in order to describe the variables themselves, the relationships between them, measure differences between the various groups, or the groups in relation to the sample overall. Frequency tables and histograms were compiled to show general statistical patterns. Microsoft Excel was used to determine the Standard Deviations of the data.

Second, in addition to describing the data by use of frequency distributions, the relationship between variables were described and tested for statistical significance. Testing for significance allows us to estimate the likelihood that a relationship between variables in a sample actually exists in a population and is not simply the result of chance (Marczyk et al, 2005). In seeking the significance of the data, the primary index is the p-value. The p-value represents the probability of chance error in determining whether a finding is valid and thus representative of the population, or collected data (Marczyk et al, 2005). For example, in examining the correlation between 'x' and 'y', a p-value greater than 0.05 would indicate that there was a greater than 5 percent probability that a finding, such as one between the Meals on Wheels /No Meals on Wheels groups, might have been by chance and as a result one could assume that there was no significant relationship between the variables in those groups (Marczyk et al, 2005). The standard level of significance used to justify a claim of a statistically significant effect is 0.05. The term statistically significant has become synonymous with the value being less than or equal to 0.05 (Dallal, 2008A).

Third, beyond the use of descriptive statistics to describe and examine associations between variables in data sets is the use of inferential statistics. Inferential statistics are used to answer questions about the greater population using representative samples in an

attempt to draw inferences about the populations from which the samples were drawn (Marczyk et al, 2005). They also help us to draw conclusions beyond the immediate samples and data. For example, inferential statistics could be used to imply that there is a link between certain group responses on the QoL Survey, such as between the home alone/not home alone groups. The use of inferential statistics allows a researcher to draw general conclusions about the population on the basis of the findings identified in a sample (Marczyk et al, 2005). Through inferential statistics, logical assumptions were made concerning various statistical associations and results from each statement, section, and sub-groups from the QoL Survey. Also, verbatim comments from the participants of the QoL Survey were presented when appropriate.

Fourth, in order to obtain p-values, the Mann-Whitney U test will be used through the use of SPSS. The Mann Whitney U test is the alternative test to the student t-test. The Mann-Whitney U test is a non-parametric test that is used to compare two population means that come from the same population. To support the QoL Survey data, the Mann-Whitney U test will be used to compare sub-groups such as Home Alone/Not Home Alone, Female/Male, etc. This test was used instead of the student t-test because of the nature of the collected data. One reason is that the Mann-Whitney U test is a non parametric test; hence it does not assume any assumptions related to the distribution of variables. Also, the student t-test assumes that the sample variables are normally distributed, whereas the data variables gathered from the QoL survey are not normally distributed.

5.0 Research Results

5.1 Introduction

The Research Results Chapter is composed of three different sections. Section, 5.2, describes the sample itself, such as family situation(s) and the publicly funded home help services which the participants were receiving. Section 5.3 examines statistics gathered from the QoL Survey. Descriptive statistics of each section of the QoL Survey, such as survey and statement means, trends, standard deviation and dispersion of the data, will be identified both at the individual and group level(s). Mann-Whitney U test results. Section 5.4 contains the statistical analysis of information gathered from selected questions from each participants MDS – Home Care assessment in a comparison with selected statements and groups (i.e. the home alone group, etc.) from the QoL Survey.

5.2 Description of the Sample

5.2.1 Family Situation and Services

Of the thirty participants who signed the informed consent and were subsequently interviewed by the researcher, fourteen were male and sixteen were female. Nine out of thirty participants still had a living partner and were therefore living with the partner and in some cases extended family in their own home. Twenty one participants were living alone in their home.

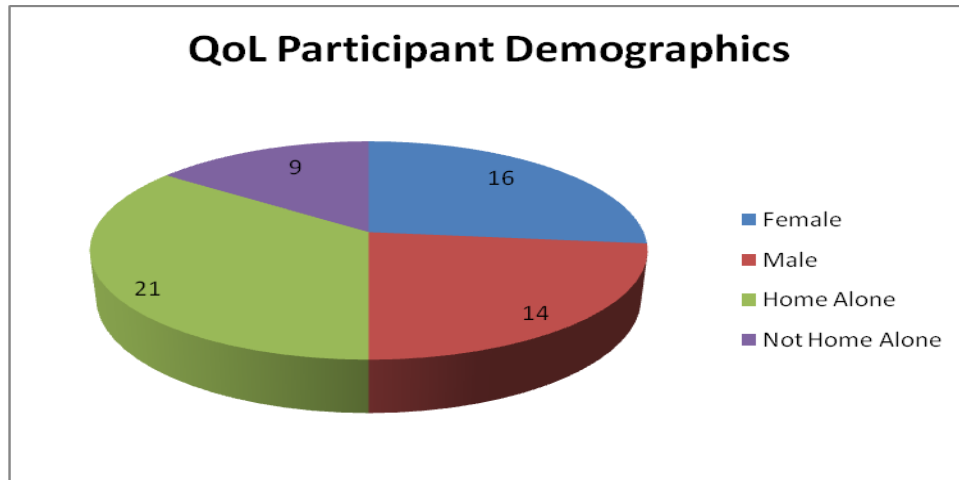


Figure 5.1 The frequency distribution of QoL participants' gender and home vs. home alone status.

All the participants were living in their own homes, while twenty nine out of the thirty indicated verbally that continuing to live in their own home was a high priority in their own QoL. One out of the thirty participants, a widow, indicated that although she very much enjoyed living in her own home, the sense of solitude made her lonely at times. Regarding the public/health workers that assisted her at home, she remarked that they came and left too fast, never stopping for a cup of tea with her.

5.2.2 Publicly Funded Home Help Services

All thirty of the participants were receiving some sort of publicly funded health, social or community support services in their home. These services were provided in order to assist the person to remain living in their own home. Figure 5.2 outlines the types of services that each person was receiving. At baseline, the thirty participants were receiving publicly funded services from five different areas. Services provided were: gardening, health care support, house cleaning, showering/dressing support, and meals on wheels. A majority of the participants who were receiving home domestic assistance, i.e., house cleaning services, had recently had their weekly allowance cut from one day per week/two hours, down to one day per week/one and a half hours by the CDHB. This had caused varying degrees of concern among some of the participants as they would get less

help. Their reported concern were due to problems they experienced with activities of daily living, such as bending over to clean a table, reaching up to clean a window, or the repetitive motion of vacuuming the floor. Of the six participants receiving meals on wheels, one was female vs. five males. On average, each participant was receiving 1.866 outside services into their home. This ranged from ten participants who were only receiving the minimum of one outside service, to one who was receiving a total of four outside services. For statistical purposes, those participants who were receiving ‘Health Care’ needs at home and those receiving ‘Showering’ help at home were further grouped together into a ‘Personal Care’ sub-group. This was done for the purposes of examining means and p-values when compared to those participants who were not receiving any health care assistance or showering assistance at home.

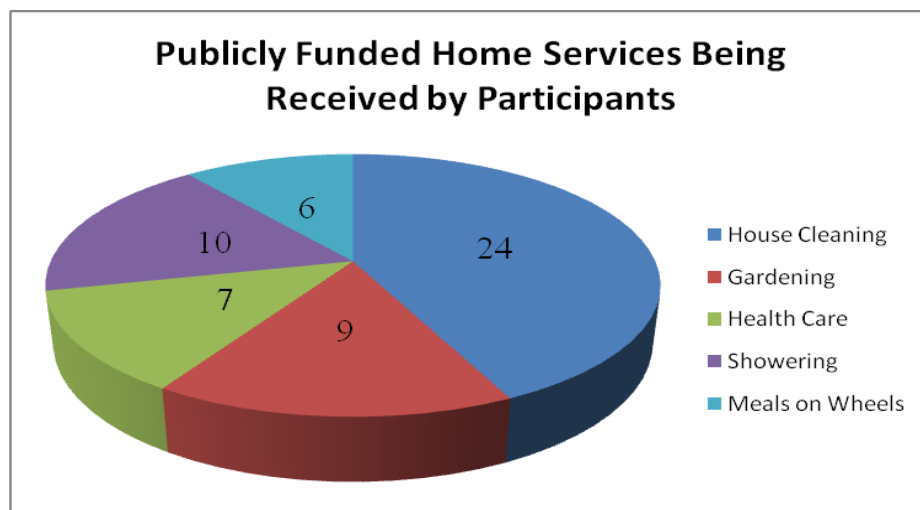


Figure 5.2 Numbers of participants who were receiving selected publicly funded services in their homes.

5.3 Quality of Life Survey Results

5.3.1 Section A. Privacy

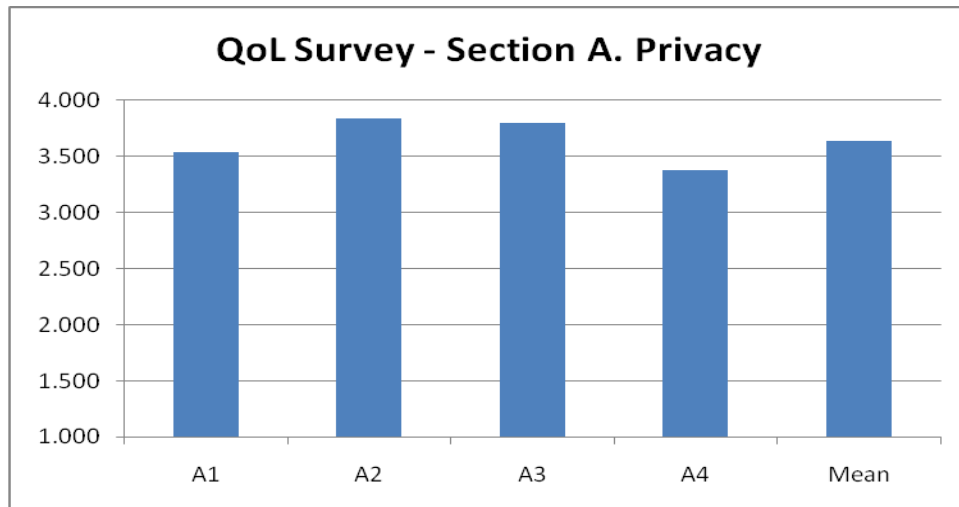


Figure 5.3 Results from QoL Survey Section A. Privacy

- A1 I can be alone when I wish.
- A2 I can have a private conversation when I wish.
- A3 My privacy is respected when people care for me.
- A4 My personal information is kept private.

Section A. of the QoL Survey examines Privacy. The overall average for Section A., on a scale of 0 to 4, (Never to Always) was 3.635. The Section A mean, when compared to the overall survey mean of 3.399, would seem to indicate that participants were in agreement about their comparatively high QoL with regards to Privacy. In this section there are four statements of which statement A2, “I can have a private conversation when I wish”, garnered the highest overall mean at 3.833, with A3, “My privacy is respected when people care for me”, close with a mean of 3.800. Statement A4 had the lowest average overall mean at 3.375. In total, there were eighty two scores of 4 – Always out of a total of one hundred and twenty responses. A4, “My personal information is kept private”, brought about much conversation and uncertainty from participants regarding their proper response. According to the participants, this was due to the nature of the statement itself, but also the wording of the question. Many of the participants were unsure about what was done with their private information, who it was shared with and how, once the information was given. This caused six participants to respond with a score of 6 (Did not Know), which was the most ticks of ‘6’ for the entire survey. The standard deviation for

each statement within Section A was: A1 = 0.730, A2 = 0.461, A3 = 0.484, and A4 = 0.647. The standard deviation for the QoL Survey as a whole was 0.466. Overall, the results would seem to indicate that the participants closely identified with “Always” with regards to their Privacy and QoL.

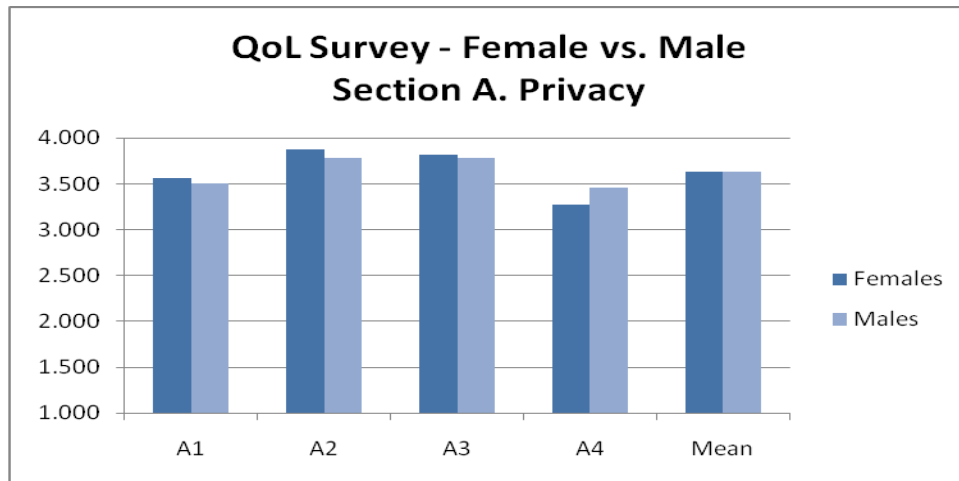


Figure 5.4 Female vs. male means for Section A. Privacy.

When examining the responses to the statements based upon gender, the results show an overall mean for females of 3.631 while males had an overall mean of 3.633. This represents a negligible difference in mean between females and males of 0.002. Statement A4, “My personal information is kept private”, revealed the largest disparity between females and males at 3.272 compared with 3.462 respectively. It is speculation to enquire as to why this is so, but three of the widows mentioned to the researcher that their former husband had dealt primarily with bills, paperwork, insurance etc. Now that they were on their own, they found it difficult at times to come to terms with this household task, and bore various amounts of uncertainty about it. Females may have felt less confident than men that their information was kept private. Both scores more closely aligned with “Most of the Time”, than the Section mean and “Always”.

When comparing the means of each statement in Section A between various groups using the Mann-Whitney U test, there were no statistically significant differences found. The Mann-Whitney U test was performed on the females/males groups, the meals on

wheels/no meals on wheels groups, personal care/no personal care groups, and the home alone/not home alone groups.

5.3.2 Section B. Food and Meals

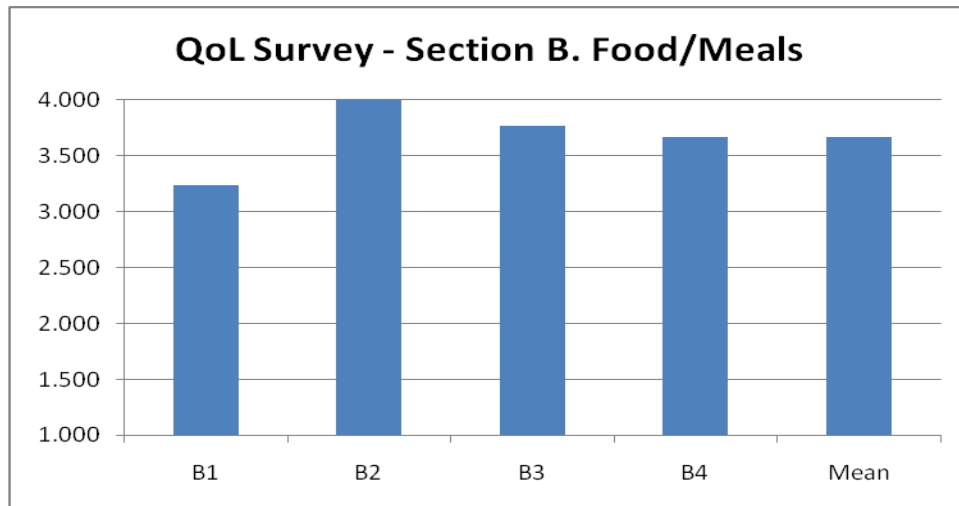


Figure 5.5 Overall results from QoL Survey Section B

- B1 I get my favourite foods.
- B2 I get enough to eat.
- B3 I have enough variety in my meals.
- B4 I enjoy mealtimes.

Section B. examines Food and Meals. The overall mean for this section was 3.667. This would seem to indicate that the participants closely identified Food and Meals with ‘Most of the Time’ to ‘Always’ with regards to the four statements. In this section there were four statements, with the highest overall mean being 4.000 for statement B2, “I get enough to eat”. This mean was achieved with twenty four participants eating their own prepared meals compared with six participants who received meals on wheels at varying times throughout the week. The lowest overall mean was B1, “I get my favourite foods”, which had a mean score of 3.233. B1 had six scores of 1 – Rarely or 2 – Sometimes, and twenty four scores of 3 – Most of the Time or 4 – Always. The standard deviation for each statement within Section B was: B1 = 0.858, B2 = 0.000, B3 = 0.504, and B4 =

0.547. Statement B2 had a maximum score of 4.000 which accounts for a standard deviation of 0.000. The high standard deviations on B1, B3 and B4 could be accounted for by the difference in responses of those receiving meals on wheels vs. not receiving meals on wheels. The large standard deviation on statement B1 could be partially due to the large difference of 0.500 from the meals on wheels/no meals on wheels groups, which had the highest mean difference of any of the comparison groups (Female/Male, Personal Care/No Personal Care, Home Alone/Not Home Alone).

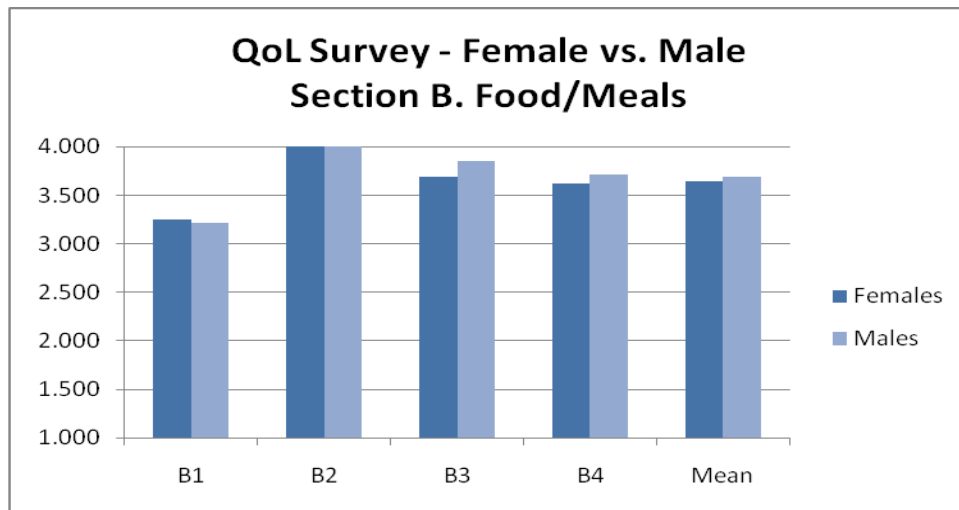


Figure 5.6 QoL Survey – Female vs. Male Section B Food/Meals

When examining the responses to the statements in Section B based upon gender, the results show an overall mean for females of 3.641 while males had an overall mean of 3.696. This accounts for an overall difference in mean between females and males of 0.055. As expected, B2, “I get enough to eat”, had a mean of 4.000 for both females and males. The largest disparity in means came from B4, “I enjoy mealtimes”. Females had a mean of 3.625 while males had a mean of 3.714. The overall mean for B4 was 3.667. Again, all scores more closely aligned towards the responses ‘Most of the Time’ to ‘Always’.

When investigating statements based upon meals on wheels, the results show an overall mean in Section B of 3.542 for the meals on wheels group, as opposed to the mean of 3.689 for the no meals on wheels group. When comparing these means to the overall QoL

Survey mean of 3.399, both groups had a higher mean. Of those participants who were receiving meals on wheels, five out of six responded to B4 with a score of 4 - Always, with an overall mean of 3.833, compared to the no meals on wheels mean of 3.625. It could be speculated that the higher mean for the meals on wheels group on B4 “I enjoy mealtimes” was due to the ease of choosing from a menu, not having to prepare a meal, and/or not having any cleanup afterwards. The low mean was the meals on wheels group from B1, “I get my favourite foods”. B1 had a low mean of 2.833, which identifies with both “Most of the Time” and also with “Sometimes”. Figure 5.7 shows the mean score for Section B for the meals on wheels/no meals on wheels groups.

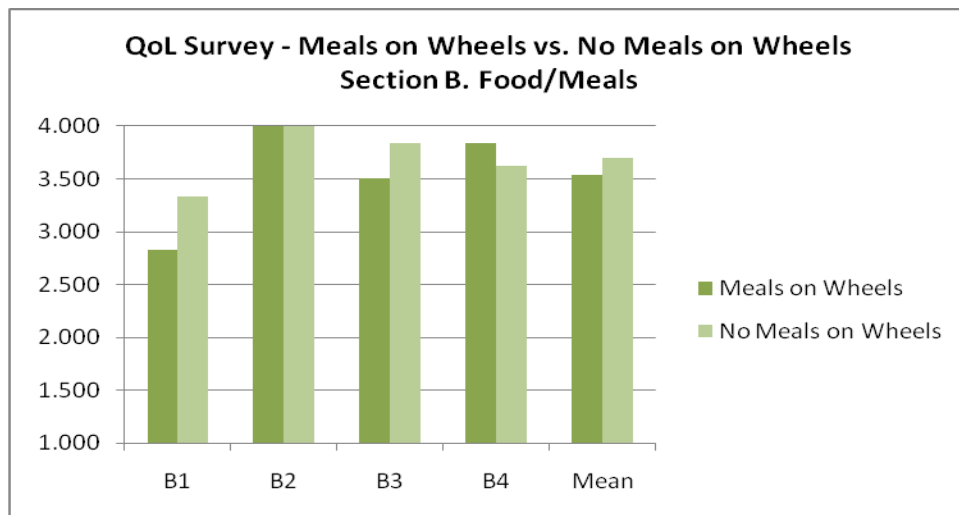


Figure 5.7 QoL Survey results from the Meals on Wheels vs. No Meals on Wheels comparison.

When examining each statement in Section B between various groups with the Mann-Whitney U test, statistically significant data was found when examining personal care vs. no personal care statement B4, “I enjoy mealtimes” in which $p = .012$. The results of B4 are shown below on table 5.2. Statement B4 will be further examined in the discussion chapter. The Mann-Whitney U test was also performed on the females/males groups, the meals on wheels/no meals on wheels groups, and the home alone/not home alone groups with no further statistically significant data.

Test Statistics

	QLSB4
Mann-Whitney U	63.500
Wilcoxon W	199.500
Z	-2.523
Asymp. Sig. (2-tailed)	.012
Exact Sig. [2*(1-tailed Sig.)]	.043

Table 5.2 Results from Mann-Whitney U test for statement B4 with $p = .012$ from Personal Care/No Personal Care comparison.

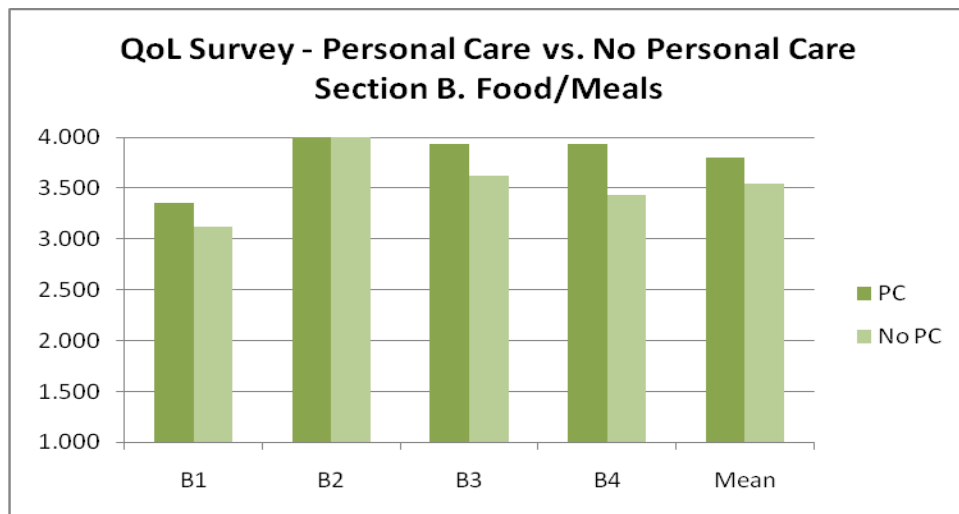


Figure 5.8 QoL Survey results from the Personal Care vs. No Personal Care comparison. This is from Section B. Food and Meals. On statement B4 $p = .012$.

5.3.3 Section C. Safety and Security

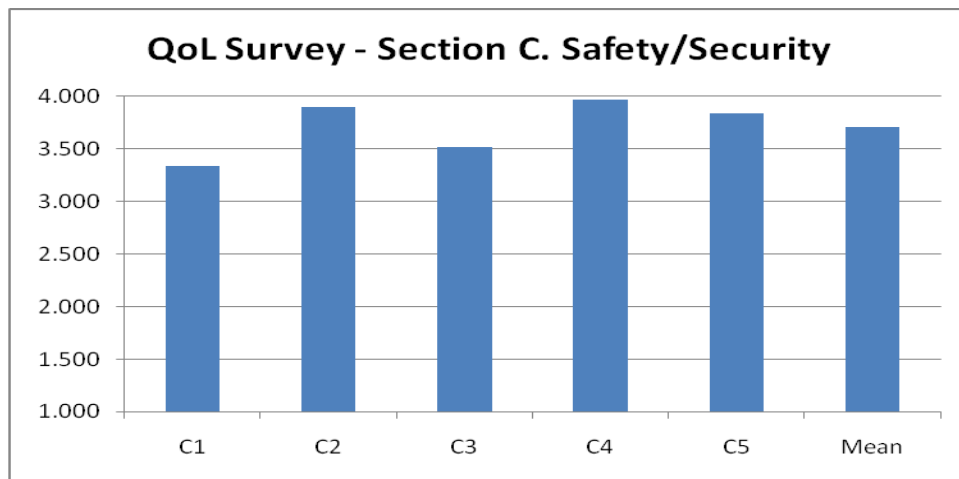


Figure 5.9 Overall results from QoL Survey Section C. Safety and Security.

- C1 I feel safe when I am alone.
- C2 I feel safe around those who provide me with support and care.
- C3 If I need help right away, I can get it.
- C4 I feel safe around my family and friends.
- C5 I feel my possessions are safe.

The overall mean for this section was 3.710. This would seem to indicate that the participants closely identified Safety and Security with “Always” with regards to the five statements. In this section there were five statements, with the highest overall mean being 3.967 for statement C4, “I feel safe around my family and friends”. It was clear during the interviews that a majority of the participants had family and friends in their lives that they trusted and were closely involved with. The lowest overall mean of 3.333 came from statement C1, “I feel safe when I am alone”. Many of the participants reported being aware of rising crime rates in New Zealand, which would partially account for this lower mean. Also contributing to the lower mean of C1 was the possibility of an accident or health issue when they were alone. There were sixteen scores of 4 – Always, along with four scores of 2 – Sometimes, or less. With regards to the mean score of 3.333 for C1, the

mean score for those participants who were home alone was higher at 3.381. The standard deviation for each statement within Section C was: C1 = 0.922, C2 = 0.305, C3 = 0.829, C4 = 0.183, and C5 = 0.379. Both C1 and C3 had a larger mean difference in the female vs. male comparison which could account for the larger deviations. C1 also had a wide spread of variance across the overall group. Across all group comparisons, statement C4 had very close mean scores. This would account for the low standard deviation.

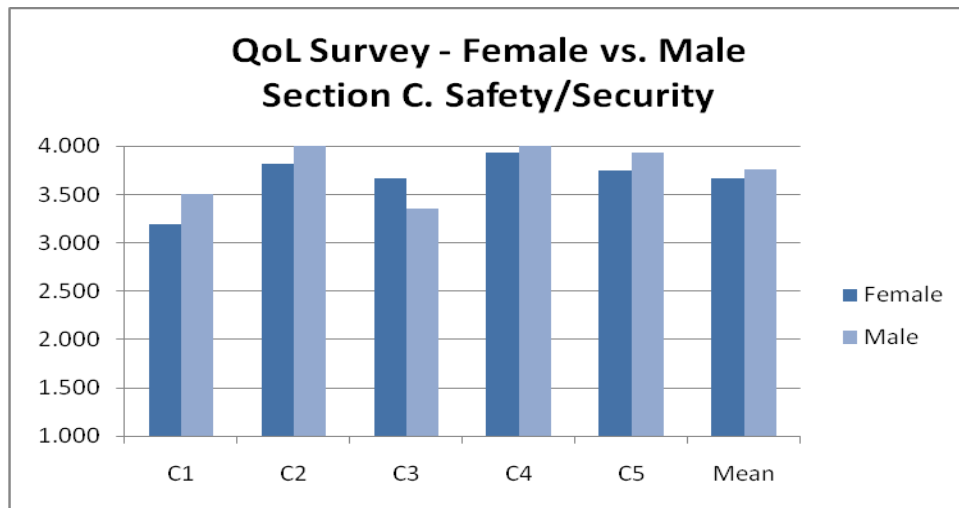


Figure 5.10 QoL Survey – Female vs. Male Section C Safety/Security mean results.

When examining the responses to statements relating to safety and security according to gender, the results show an overall mean for females of 3.671 while males had an overall mean of 3.757. A difference in mean between females and males of 0.086. On statement C1 males had a higher mean by 0.312 than females, while on statement C3 “If I need help right away, I can get it” females had a higher mean than males by 0.309. Across both female and male groups, mean scores were more closely aligned with “Always” with regards to their Safety and Security statements. Statement means for Section C for the home alone/not home alone groups are expressed below on Figure 5.11.

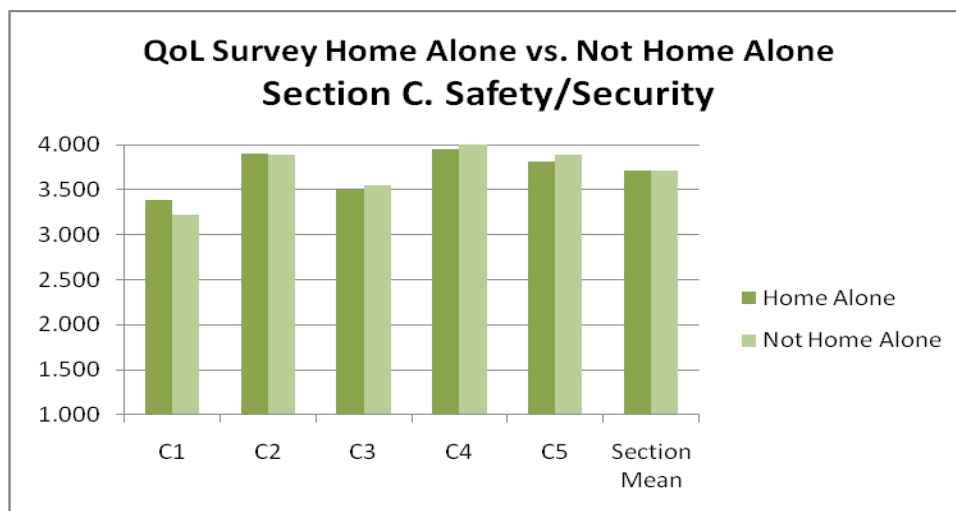


Figure 5.11 Home Alone results from QoL Survey Section C. Safety and Security.

In examining the results from the Home Alone sample, the mean of 3.710 matched that of the overall survey result for Section C. The high and low means for the Home Alone group matched that of the overall sample. The highest mean of 3.952 came from C4, “I feel safe around my family and friends”, while the lowest mean of 3.381 came from C1, “I feel safe when I am alone”. C1 had eleven scores of 4 – Always out of twenty one, with two scores of 2 – Sometimes, as well.

When examining the responses of each statement in Section C by various groups, using the Mann-Whitney U test, there were no statistically significant differences found. The Mann-Whitney U test was performed for females/males groups, the meals on wheels/no meals on wheels groups, Personal Care/No Personal Care groups, and the home alone/not home alone groups.

5.3.4 Section D. Comfort and Environment

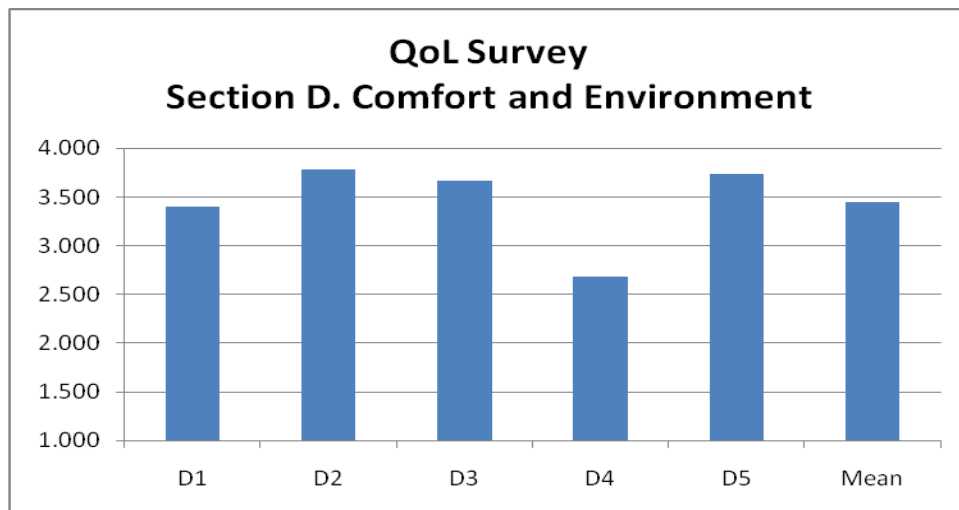


Figure 5.12 Overall results from QoL Survey Section D. Comfort and Environment.

- D1 I get the services I need.
- D2 I would recommend this program to others.
- D3 I can easily go outdoors if I want.
- D4 I tend to be happier than most other people.
- D5 My home is as clean as I would like.

Section D examines Comfort and Environment. The overall mean was 3.451. This overall mean would seem to indicate that the participants associated more with “Most of the Time” than “Always” with regards to the statements regarding their Comfort and Environment and QoL. There were five statements in the section, with the highest mean being for statement D2 at 3.778, “I would recommend this program to others”. D2 had a high percentage of participants scoring 4 – Always. The lowest mean came from statement D4 at 2.679, “I tend to be happier than most other people”. D4 had eleven scores out of twenty nine that were scored 2 – Sometimes, or less. Regarding statement D2, there was a level of confusion over what “...program...” it was referring to as the section was covering Comfort and Environment. Largely, the participants had nothing but praise for the programs which assisted them to live in their own homes and this is

reflected by this high score. Although it is debatable whether or not the participant confusion over the location of the question contributed to the score being lower or higher than it would have been if it was grouped in Section F. Respect or Section G. Worker Responsiveness. Statement D4 was met with many interesting comments. Many participants did not like the statement itself as it appeared to them to be too subjective. One person went as far as to purposely ask the researcher to write down on the survey “This question is stupid!” Needless to say, there were some visceral reactions regarding this statement due to the subjective nature of happiness itself. Henry David Thoreau wrote about happiness “Happiness is like a butterfly: the more you chase it, the more it will elude you, but if you turn your attention to other things, it will come and sit softly on your shoulder (nsrider.com, 2010).” It is difficult to tell what makes a person happy, or at times how to tell a person is happy. It is quite possible that the subjective nature of this statement and the dislike that many participants had for it, contributed heavily to its low mean. The standard deviation for each statement within Section D was: D1 = 0.814, D2 = 0.641, D3 = 0.802, D4 = 0.905, and D5 = 0.521. The large standard deviation for D4 could be due to ambivalence over the statement itself. The large deviations in D1 and D3 follow large differences in mean scores on those two statements when looking at means of females and males.

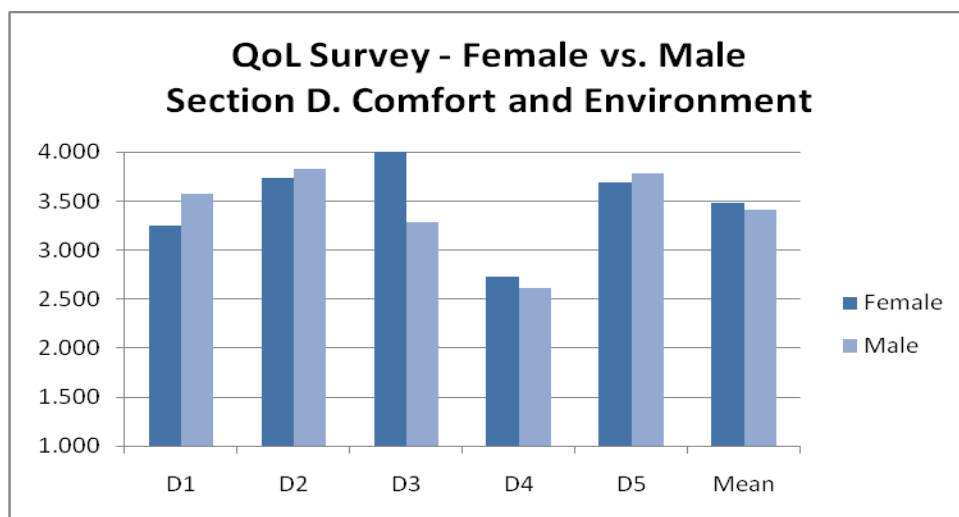


Figure 5.13 QoL Survey – Female vs. Male Section D. Comfort and Environment means. On statement D3 $p = .010$.

When examining the responses to the statements based upon gender, the results show an overall mean for females of 3.481 while males had an overall mean of 3.418, an overall difference in means between females and males of 0.063. Both scores, like the overall Section mean, aligning closer to the “Most of the Time” with regards to the QoL and Comfort and Environment. Statements D1 and D3 showed the largest disparity in means between men and women. D1, “I get the services I need”, has a mean of 3.250 for females while males had a mean of 3.571, a difference in mean scores of 0.321. The largest difference in means came from D3, “I can easily go outside if I want to”. Females had a mean of 4.000, meaning that all females ticked the “Always” box, while males had a mean of 3.286, closer to the “Most of the Times” box, for a difference of 0.714. The QoL survey does not delve into medical issues and/or conditions, so it is difficult to explain this difference between the two. Several of the men did have obvious physical problems which would have made it difficult for them to go outside easily.

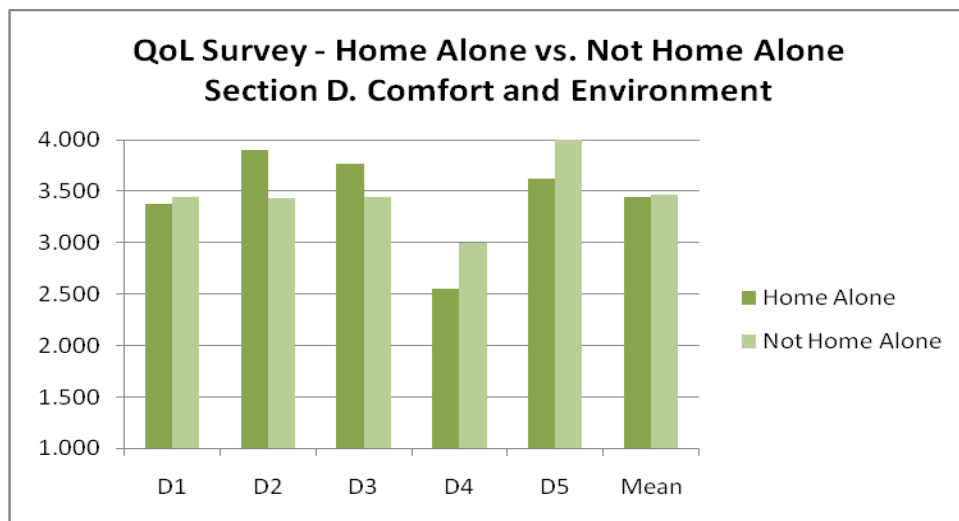


Figure 5.14 QoL Survey means from Home Alone vs. Not Home Alone comparison.

When examining the means of each statement by various groups using the Mann-Whitney U test, the difference between females and males was found to be statistically significant for statement D3, with a $p = .010$. In examining the difference between the responses of those home alone against not home alone, statement D5, “My home is as

clean as I would like it”, was found to be $p = .053$, placing it just outside of the acceptable range of statistical significance. The difference between personal care and no personal care for Statement D3 also was found to have a statistically significant at $p = .010$, while statement D5 placed just outside of the acceptable range of statistical significance with $p = .051$ within the same comparison. Statement D3 will be further examined in the discussion Chapter. The Mann-Whitney U test was also performed on the home alone/not home alone groups, and the meals on wheels/no meals on wheels groups. Table 5.3 below shows the Mann-Whitney U test for D3 from the personal care/no personal care groups.

Test Statistics

	QLSD3
Mann-Whitney U	72.000
Wilcoxon W	177.000
Z	-2.564
Asymp. Sig. (2-tailed)	.010
Exact Sig. [2*(1-tailed Sig.)]	.101

Table 5.3 P = .010 for statement D3 in the personal care/no personal care comparison.

Test Statistics

	QLSD3
Mann-Whitney U	72.000
Wilcoxon W	177.000
Z	-2.564
Asymp. Sig. (2-tailed)	.010
Exact Sig. [2*(1-tailed Sig.)]	.101

Table 5.4 P = .010 for statement D3 in the female/male comparison.

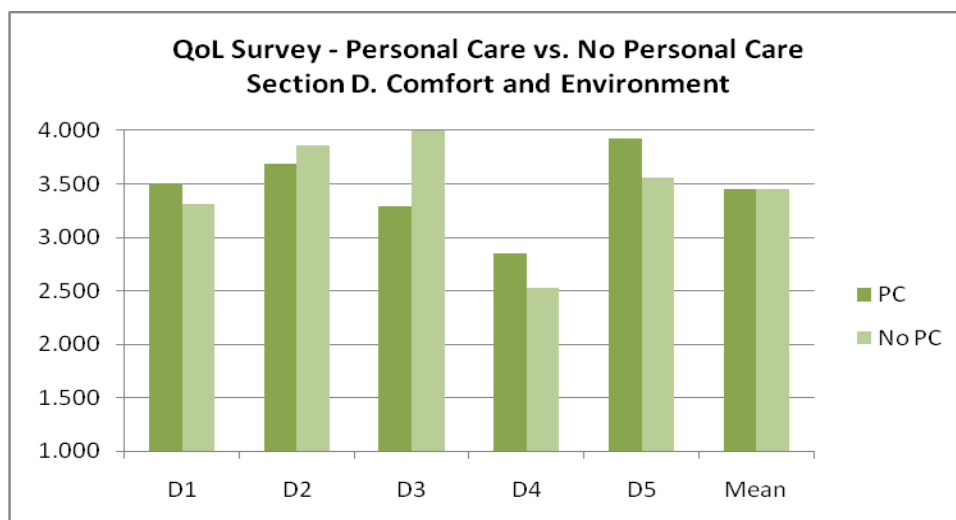


Figure 5.15 QoL Survey means from Personal Care vs. No Personal Care groups.
Statement D3 $p = .010$.

5.3.5 Section E. Autonomy

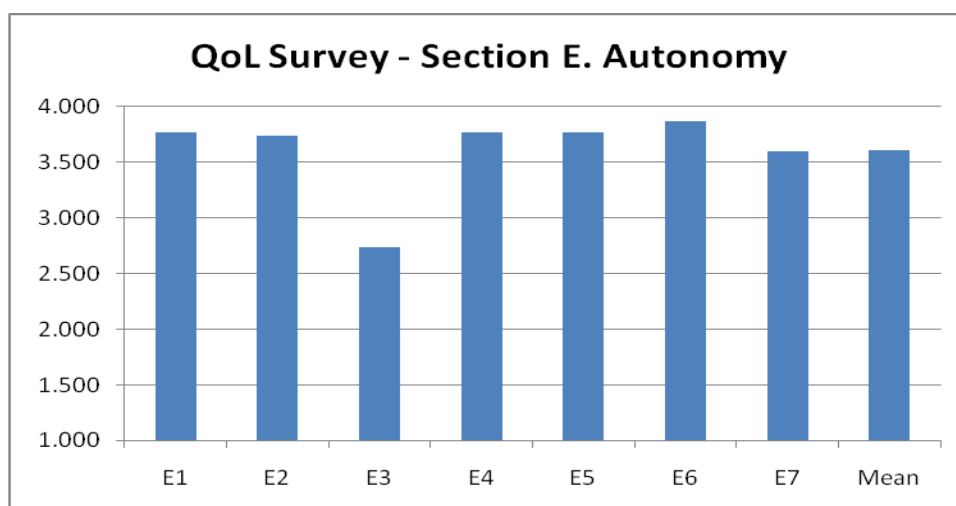


Figure 5.16 Overall mean scores from QoL Survey Section E. Autonomy.

- E1 I decide when to go to bed and get up.
- E2 I decide how to spend my time.
- E3 I can go where I want on the “spur of the moment.”
- E4 I control who comes into my home.

- E5 I decide how my money is spent.
 E6 I live where I want.
 E7 I can have a bath or shower as often as I want.

Section E. of the QoL survey was on Autonomy. The overall mean was 3.605. This indicates that overall the participants were more often responding to statements regarding Autonomy with ‘Always’. There were seven statements in this section. The highest mean, 3.867, came from statement E6, “I live where I want”. As established earlier, living in one’s own home is a strong indicator of quality of life in the elderly population. Clearly a large majority of the participants enjoyed living in their own homes and viewed it is an integral part of their own self perceived quality of life. The lowest mean, 2.733, came from statement E3, “I can go where I want on the spur of the moment.” This lower mean indicates that more participants responded with answers of ‘Sometimes’ and “Most of the Time”. The standard deviation for each statement within Section E was: E1 = 0.568, E2 = 0.583, E3 = 1.172, E4 = 0.568, E5 = 0.817, E6 = 0.434 and E7 = 0.855. These high standard deviations all indicate a high range of variability in answers. Statement E3 was found to have large disparities between mean scores on the female/male and personal care/no personal care groups. This could account for the large deviation. Statement E5 also had a large mean difference in these same comparisons.

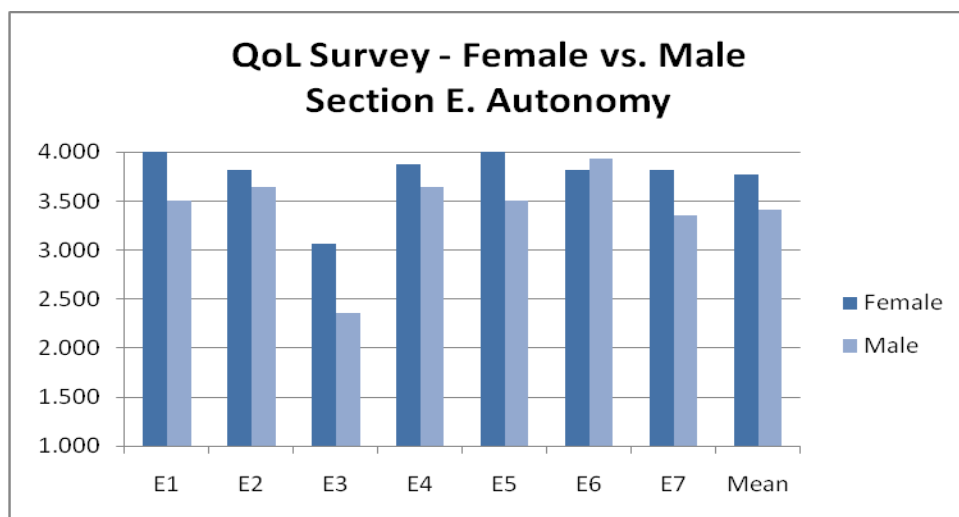


Figure 5.17 QoL Survey means from Section E. Autonomy female vs. male. Statement E1 was found to have a statistically significant p-value of 0.10.

When examining the responses to the statements based upon gender, the results show an overall mean for females of 3.768 while males had an overall mean of 3.418. This indicates that males were more likely than females to tick ‘Always’, while females were most often ticking ‘Most of the Time’. This accounts for an overall difference in mean between females and males at 0.350. Statement E3 resulted in the largest disparity between females and males of 0.706. This resulted in most males scoring ‘Most of the Time’, while a majority of females scored ‘Sometimes’. The statement with the closest mean scores across genders, 0.116, came from E6 “I live where I want”. Both females and males agreed, with the exception of one participant, that they indeed wanted to continue living in their own home.

When examining the differences in responses to each statement in various groups within the section using the Mann-Whitney U test, the three statistically significant differences were found. In examining the females/males groups, statement E1, “I decide when to go to bed and when to get up”, had a $p = .01$. This is indicated on table 5.5 below.

Test Statistics	
	QLSE1
Mann-Whitney U	72.000
Wilcoxon W	177.000
Z	-2.564
Asymp. Sig. (2-tailed)	.010
Exact Sig. [2*(1-tailed Sig.)]	.101

Table 5.5 Mann-Whitney U results for statement E1 on the female vs. male comparison

Statement E5, “I decide how my money is spent”, had a $p = .055$, placing it just outside of the acceptable range of significance. When examining the different responses from personal care vs. no personal care comparison, statements E3 and E7 were found to have statistically significant p-values of $p = .029$ and $p = 0.17$. These are indicated on table 5.6 below.

Test Statistics		
	QLSE3	QLSE7
Mann-Whitney U	62.000	69.500
Wilcoxon W	167.000	174.500
Z	-2.180	-2.388
Asymp. Sig. (2-tailed)	.029	.017
Exact Sig. [2*(1-tailed Sig.)]	.038	.077

Table 5.6 Mann-Whitney U results for statements E3 and E7 on the Personal Care vs. No Personal Care comparison.

Statement E5 had a p-value of $p = .055$, placing it just outside the acceptable range of significance. Statements E1, E3, and E7 will be further examined in the Discussion Chapter. The Mann-Whitney U test was also performed on the meals on wheels/no meals on wheels and home alone/not home alone groups.

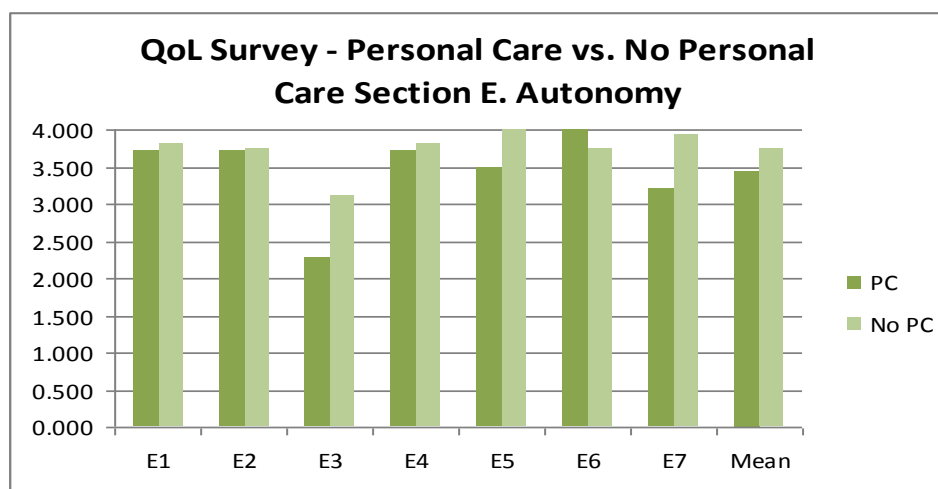


Figure 5.18 QoL Survey results from Personal Care vs. No Personal Care comparison.

5.3.6 Section F. Respect

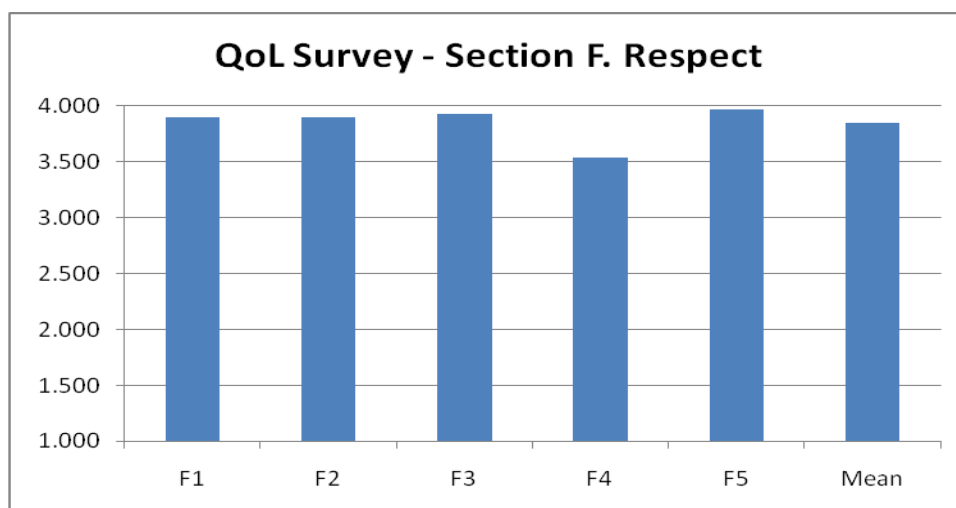


Figure 5.19 Overall results from QoL Survey Section F. Respect.

- F1 I can express my opinion without fear of consequences.
- F2 I am treated with respect by the people involved in my support and care.
- F3 _____ staff (fill in the program name or type of staff) respect what I like and dislike.
- F4 People ask before using my things.
- F5 _____ staff (fill in program name or type of staff) take advantage of me. (scores are reversed for this statement)

Section F was on Respect. The overall mean was 3.845. There were five statements in this section. The highest overall mean, 3.966, came from F5 “_____ staff (fill in program name or type of staff) take advantage of me”. This was the only question on which the scores were reversed. A score of zero meant ‘Always’ while a score of four meant ‘Never’. There were a total of twenty nine scores of four and one score of three. The respondent reporting the lower score of three indicated that the staff had good intentions in taking advantage of the participant in order to help with needed assistance around the house, and had no bad intentions. The lowest mean, 3.536, came from F4 “People ask before using my things”. The comment most often made concerning this

statement was that the support workers who came into their homes went about their tasks quickly, often times not conversing with the participants. The standard deviation for each statement within Section F was: F1 = 0.305, F2 = 0.305, F3 = 0.272, F4 = 0.838, and F5 = 0.192. Other than statement F4, these small standard deviations indicate scores that are congregated closely around the section mean of 3.845. Statement F4 had large differences in mean score in comparisons between females and males.

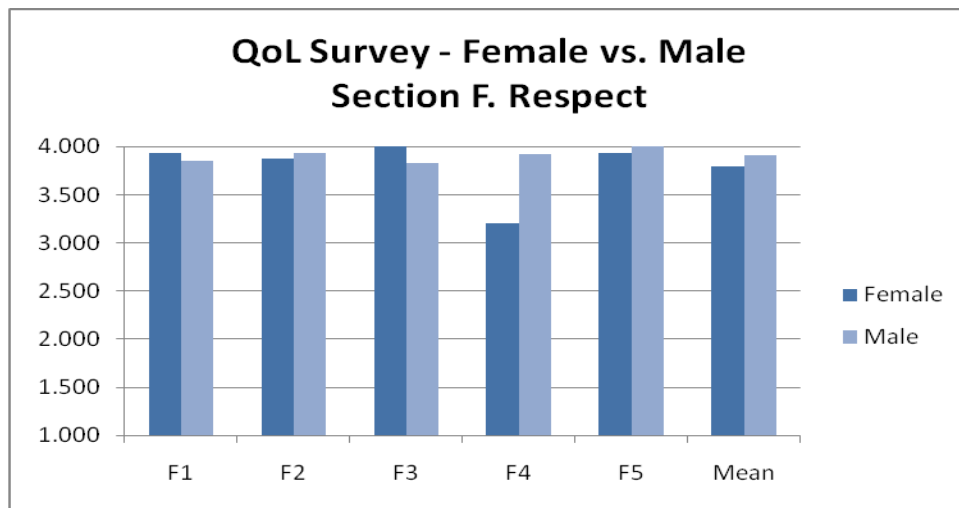


Figure 5.20 QoL Survey – Female vs. Male Section F. Respect mean results.

When examining the responses to the statements based upon gender, the results show an overall mean for females of 3.790 while males had an overall mean of 3.908, an overall difference of 0.118. The largest difference in mean scores was F4, where females had a mean of 3.200 and males had a mean of 3.923. This accounted for a difference of 0.723. The closest means came from F2, “I am treated with respect by the people involved in my support and care”, which only had a difference of 0.054.

When examining each statement between various groups within the section using the Mann-Whitney U test, statement F4 was found to be statistically significant with a p-value of $p = .020$ in the females/males comparison. This is indicated on table 5.7 below.

Test Statistics	
	QLSF4
Mann-Whitney U	57.500
Wilcoxon W	177.500
Z	-2.317
Asymp. Sig. (2-tailed)	.020
Exact Sig. [2*(1-tailed Sig.)]	.065

Table 5.7 Mann-Whitney U results for statement F4 on the female vs. male comparison.

Statement F4 will be further examined in the Discussion Chapter. The Mann-Whitney U test was also performed on home alone/not home alone groups, meals on wheels/no meals on wheels groups, and personal care/no personal care groups with no other statistically significant data found.

5.3.7 Section G. Worker Responsiveness

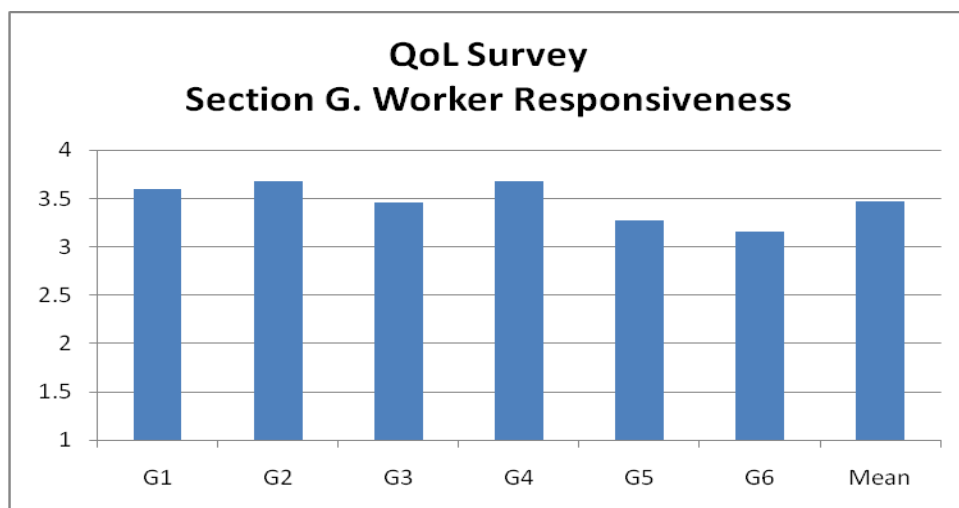


Figure 5.21 Overall results from QoL Survey Section G. Worker Responsiveness.

- G1 My services are delivered when I want them.
- G2 The care and support I get help me live my life the way I want.
- G3 _____(fill in program name or type of staff) act on my suggestions.
- G4 I can get the health services I need.

- G5 _____(fill in program name or type of staff) talk to me about how to meet my needs.
- G6 I consider _____staff (fill in program name or type of staff) member my friend.

Section G was on Worker Responsiveness. The overall mean was 3.473. There were six statements in this section. The highest mean, 3.679, was shared between G2 and G4. These statements had high numbers of participants who scored 'Always'. G2 read "The care and support I get help me live my life the way I want", while G4 read "I can get the health services I need". The lowest mean, 3.154, came from G6, "I consider a _____ staff (fill in program name or type of staff) member my friend". This low mean indicates a higher number of scores of 'Most of the Time'. Frequently this statement caused the participants to struggle to come to terms with the definition of 'friend'. As mentioned earlier, the common experience of the participants was that the outside workers came in to their homes, did their work quickly and for the most part with little conversation, and then left. Although each of the participants was grateful for the help itself, several did not necessarily consider the worker to be a friend but perhaps more of an acquaintance. The variance for each statement is as follows: The standard deviation for each statement within Section G was: G1 = 0.747, G2 = 0.723, G3 = 1.105, G4 = 0.670, G5 = 1.151, and G6 = 1.156. There were some large variation in mean scores when examining the personal care/no personal care groups, meals on wheels/no meals on wheels groups, and the females/males groups. These large variations could account for these large standard deviations.

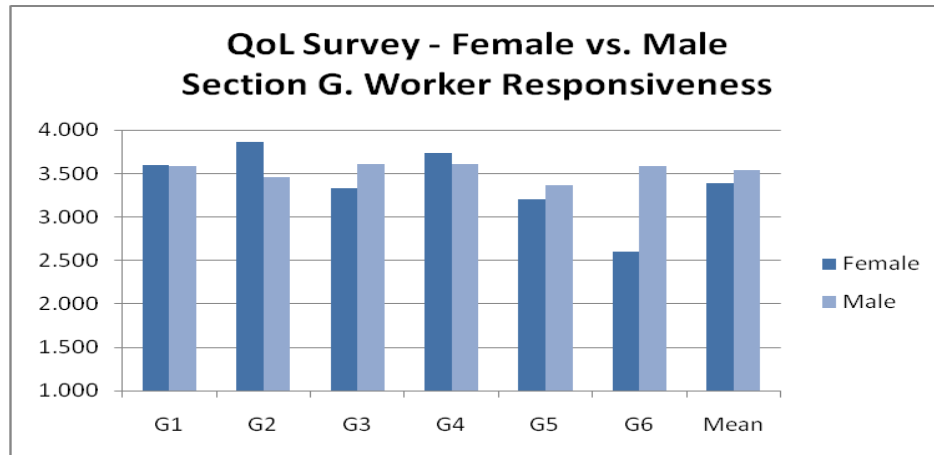


Figure 5.22 QoL Survey – Female vs. Male Section G. Worker Responsiveness mean results.

When examining the responses to the statements based upon gender, the results show an overall mean for females of 3.389 while males had an overall mean of 3.538, a difference of only 0.149 but one which showed that females tended to score more ‘Most of the Time’ than males, who tended to score more ‘Always’. The largest difference in mean scores came from G6, where females had a mean of 2.785 while males had a mean of 3.583. This accounted for a difference of 0.798, which was one of the largest differences between female vs. male scores for any statement on the survey. It also showed that a majority of males were scoring ‘Always’ while many females were scoring ‘Sometimes’ to ‘Most of the Time’. Statement G2 had an overall difference in mean of 0.405 as females had a mean of 3.867 with males at 3.462. It is interesting to note that the two of the largest differences in statement mean scores between females and males occurred in sections which related directly with feelings the participants had about the people who provided their care and supports.

When examining each statement in Section G against various groups within the section with the Mann-Whitney U test, there were no statistically significant differences found. The Mann-Whitney U test was performed on the females vs. males groups, the meals on wheels vs. no meals on wheels groups, personal care vs. no personal care groups, and the home alone vs. not home alone groups.

5.3.8 Section H. Activities and Community Integration

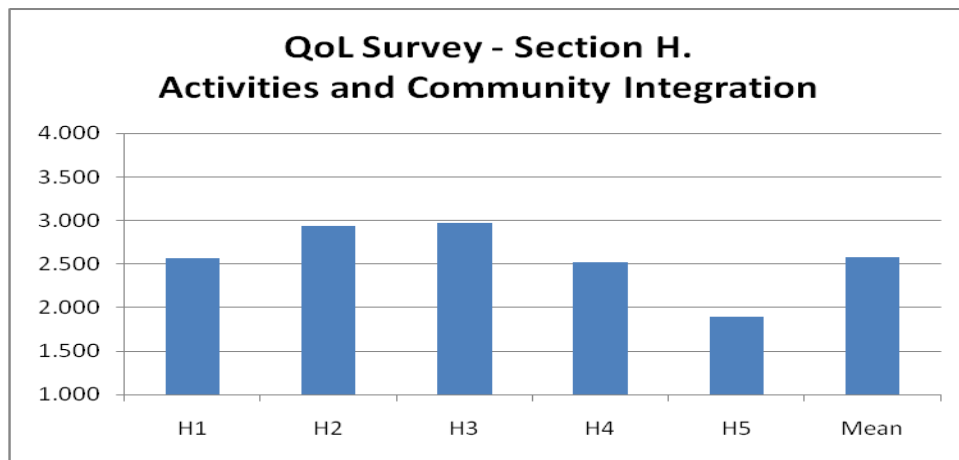


Figure 5.23 Overall results from QoL Survey Section H. Activities and Community Integration.

- H1 If I want, I can take part in activities in the community.
- H2 I can do activities that are important to me.
- H3 If I want, I can participate in religious activities that have meaning to me.
- H4 I belong to a group that sees me as a valued member.
- H5 People outside my home ask for my help or advice.

Section H was on Activities and Community Integration. The overall mean was 2.577, which was dramatically lower than any prior Section and the lowest overall score for a Section in the Survey. This indicated that a majority of participants scored ‘Sometimes’ or ‘Most of the Times’. There were five statements in this section. The highest mean, 2.967, was H3, “If I want, I can participate in religious activities that have meaning to me”. The lowest mean, 1.900, was H5, “People outside my home ask for my help or advice”. A mean of 1.900 indicates that a majority of scores were ‘Sometimes’ but with others scores also of ‘Rarely’. Several of the participants felt that due to their advanced age and slow paced lifestyle that they could give only a little help or advice to others. Others felt that it was their advanced ages that were the reason that few asked for their help or advice. The standard deviation for each statement within Section H was: H1 =

1.357, H2 = 1.112, H3 = 1.326, H4 = 1.353, and H5 = 1.029. These high standard deviations indicate a wide variability in statement scores. When looking at some of the large disparities in means between statements in the comparisons between females and males, and home alone/not home alone, these large standard deviations are more easily understood.

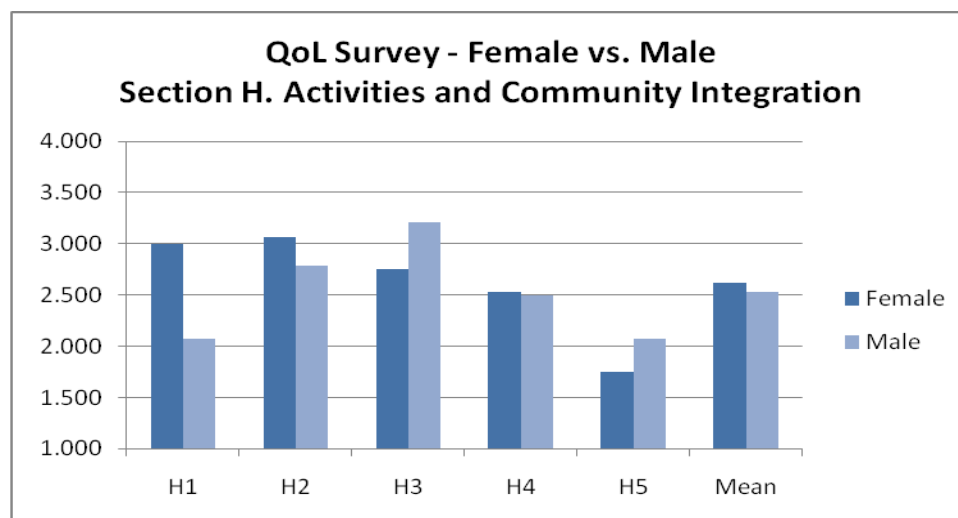


Figure 5.24 QoL Survey – Female vs. Male Section H. Activities and Community Integration mean results.

When examining the responses to the statements based upon gender, the results show an overall mean for females of 2.619 while males had an overall mean of 2.529, an overall difference of 0.090. The largest difference in mean, at 0.929, between females and males came from H1, “If I want, I can take part in activities in the community”. Ten out of the sixteen females had scores of 3 – Most of the Time or 4 – Always. On this same statement H1, only seven out of fourteen males had scores of 3 or 4. Six of the male’s scores were 0 – Never or 1 – Rarely. The closest means came from statement H4, “I belong to a group that sees me as a valued member”, which had only a difference of 0.033 between females and males but had a low overall means for both groups of 2.533 for females and 2.500 for males.

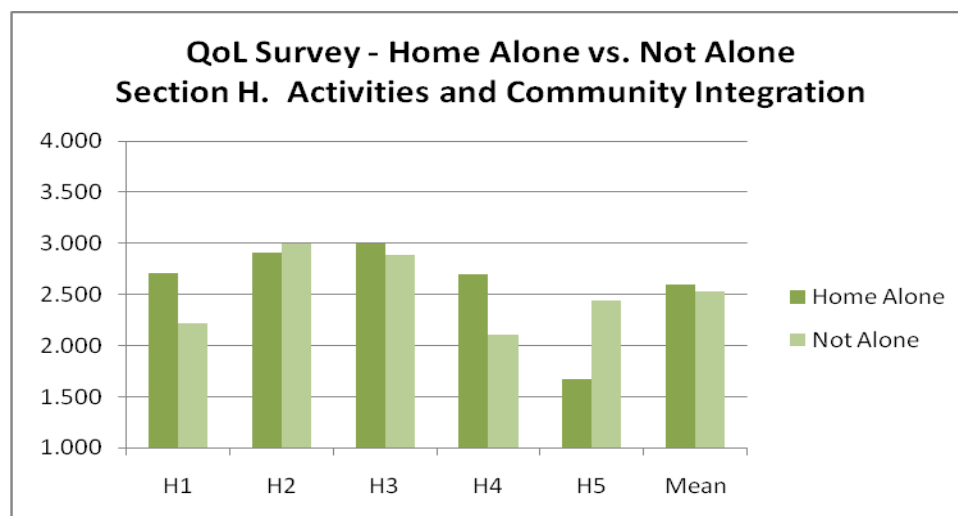


Figure 5.25 Home Alone vs. Not Home alone means for Section H. Activities and Community Integration.

When examining the means for each statement in Section H for various groups using the Mann-Whitney U test, a statistically significant difference was found on statement H5. In applying the Mann-Whitney U test to the home alone/not home alone groups, statement H5, “People outside my home ask for my help or advice”, had a p-value of $p = .050$. This is indicated on table 5.8 below.

Test Statistics	
	QLSH5
Mann-Whitney U	55.500
Wilcoxon W	286.500
Z	-1.958
Asymp. Sig. (2-tailed)	.050
Exact Sig. [2*(1-tailed Sig.)]	.077

Table 5.8 Mann-Whitney U results from statement H5 for the home alone vs. not home alone comparison.

H5 will be further evaluated in the Discussion Chapter. The Mann-Whitney U test was also applied to the female/male groups, meals on wheels/no meals on wheels groups, and the personal care/no personal care group with no further data of statistical significance found.

5.3.9 Section I. Personal Relationships

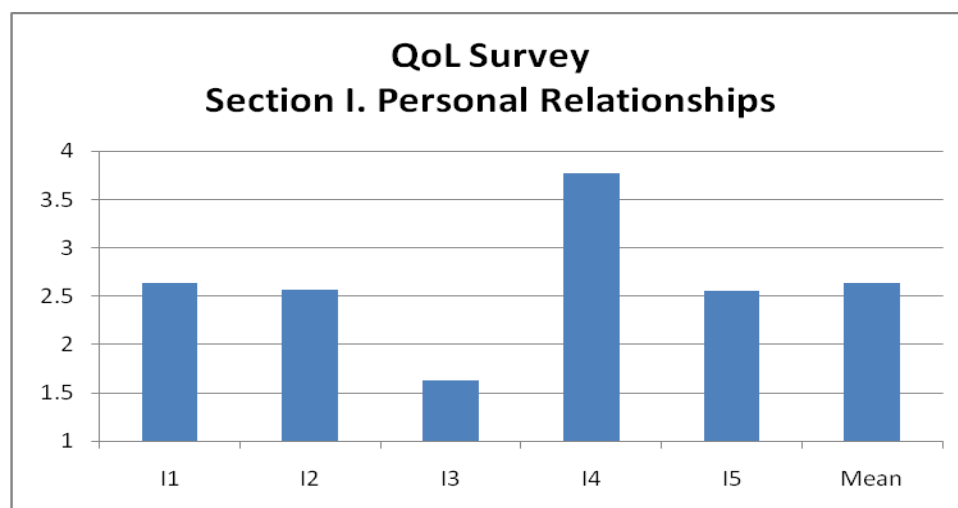


Figure 5.26 Overall results from QoL Survey Section I. Personal Relationships.

- I1 I have people who want to do things together with me.
- I2 I play an important role in people's lives.
- I3 I have opportunities for affection or romance.
- I4 I have people I can count on.
- I5 People know the story of my life.

Section I was on Personal Relationships. The overall mean was 2.631. This was the second lowest mean in the Survey and an indication that many participants scored this section 'Sometimes' and 'Most of the Time'. There were five statements in this section. The highest mean, 3.767, came from I4, "I have people I can count on". There were twenty six scores of 'Always' for this statement. It is an interesting dichotomy that in this section with a low mean score of 2.631 that such a high score would be achieved on I4. Many of the participants felt that they had family and friends in their lives that they trusted implicitly. The lowest mean, 1.633, came from I3, "I have opportunities for affection or romance" in which there sixteen scores of 0 – Never or 1 - Rarely. This score was the lowest overall score for any statement in the Survey. The common response to reading or hearing this question was a chuckle or laughter. Many participants found it

difficult to separate what they often viewed as two different concepts: affection or romance. Also, many participants stated that they were too old for either, or were widows/widowers with no opportunity. The standard deviation for each statement within Section I was: I1 = 0.964, I2 = 1.034, I3 = 1.629, I4 = 0.774, and I5 = 1.152. These large standard deviations indicate a wide variability in participant scores. These large standard deviations could be accounted for in examining the difference in means between females and males, and the home alone/not home alone groups. Statement I3 from females/males had a disparity in means of .0955 which the largest difference between females and males. I3 had an even larger disparity of 2.111 when examining home alone/not home alone. Statement I2, “I play an important role in peoples lives”, also had a large disparity in means of 0.959 when examining home alone/not home alone. These means and disparities are indicated in Figure 5.27 and Figure 5.28.

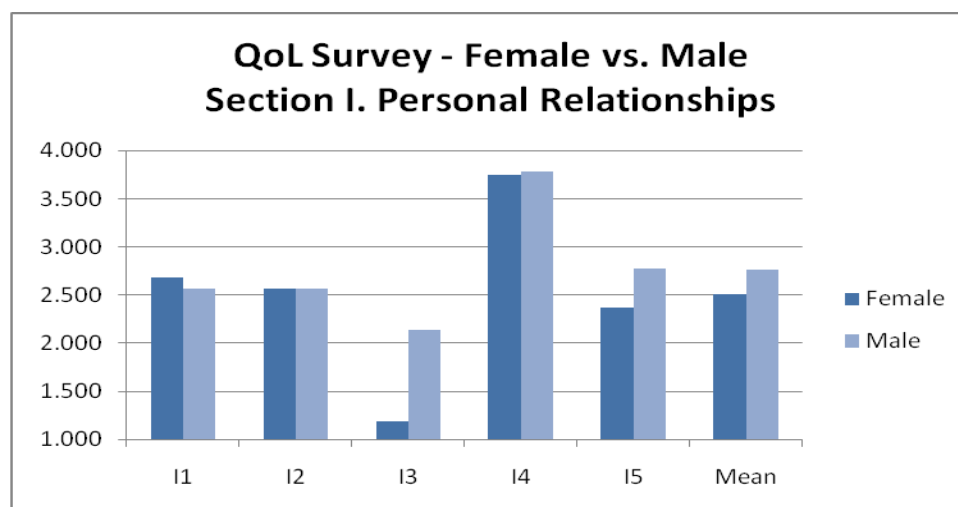


Figure 5.27 QoL Survey – Female vs. Male Section I. Personal Relationships mean results.

When examining the responses to the statements based upon gender, the results show an overall mean for females of 2.514 while males had an overall mean of 2.768. This accounted for a difference of 0.254. The largest difference in mean score, 0.955, came from statement I3, where eleven out of the sixteen females scores a 0 – Never or 1 – Rarely. Five out of fourteen males scored a 0 or 1, while six scored a 3 – Most of the Time, or 4 – Always. This was the second largest difference in female/male mean scores

from the QoL survey. The reason for this disparity is not clear, but might have much to do with the dislike of ‘affection’ vs. ‘romance’ in the statement itself. Another possible reason would be the larger population of females in the seventy five and above age group. The closest mean scores were achieved on statement I4, “I have people I can count on”, where the mean difference between males and females was only 0.036.

When examining results based upon home alone/not home alone two large disparities in scores are revealed. Statement I2 mean for not home alone was 3.222 while the home alone group had a mean of 2.263. This accounted for a difference in means of 0.959. The not home alone group had eight scores out of nine that were a 3 or 4. The home alone group had eight out of twenty one score a 3 or 4, and had thirteen score a 2 – Sometimes or less. Statement I3 had the largest disparity of any group when looking at the home alone/not home alone comparison. The not home alone group had a mean of 3.111 while the home alone group had a mean of 1.000. Fifteen out of twenty one from the home alone group scored a 1 – Rarely or 0 – Never in response to I3. Seven of nine from the not home alone group had scores of 3 – Most of the Time or 4 – Always.

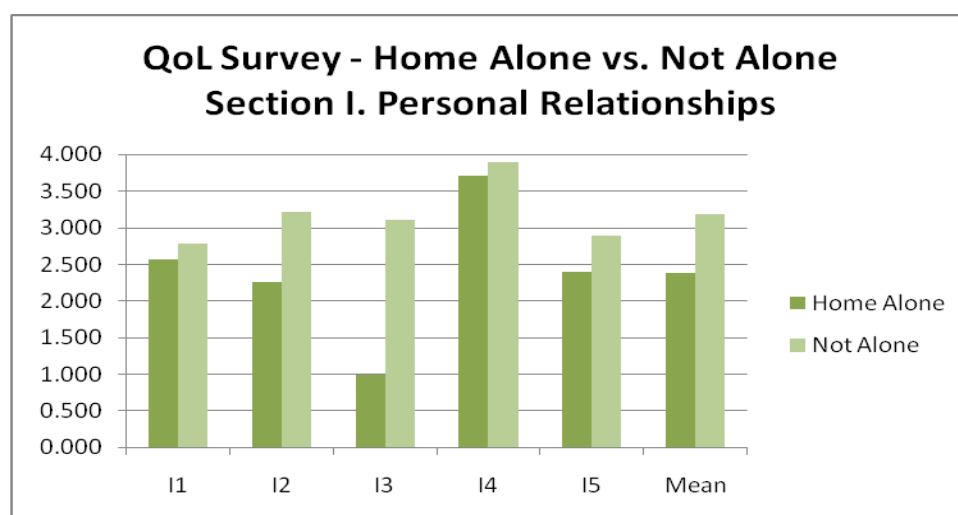


Figure 5.28 Home Alone vs. Not Alone means for Section I.

When examining the responses to each statement in Section I according to different groups, using the Mann-Whitney U test, a statistically significant difference was found on statements I2 and I3 for the home alone and not home alone group comparison. statement

I2 had a p-value of $p = .016$, while statement I3 had a p-value of $p = .001$. These results are indicated on table 5.9 below.

Test Statistics		
	QLSI2	QLSI3
Mann-Whitney U	37.000	25.500
Wilcoxon W	227.000	256.500
Z	-2.501	-3.254
Asymp. Sig. (2-tailed)	.012	.001
Exact Sig. [2*(1-tailed Sig.)]	.016	.001

Table 5.9 Mann-Whitney U results for statements I2 and I3 for the home alone vs. not home alone comparison

These scores will be further evaluated in the Discussion Chapter. The Mann-Whitney U test was also performed on the meals on wheels/no meals on wheels groups, the female/male groups, and the personal care/no personal care groups with no statistically significant data.

5.3.10 Overall Assessment of Descriptive Analysis

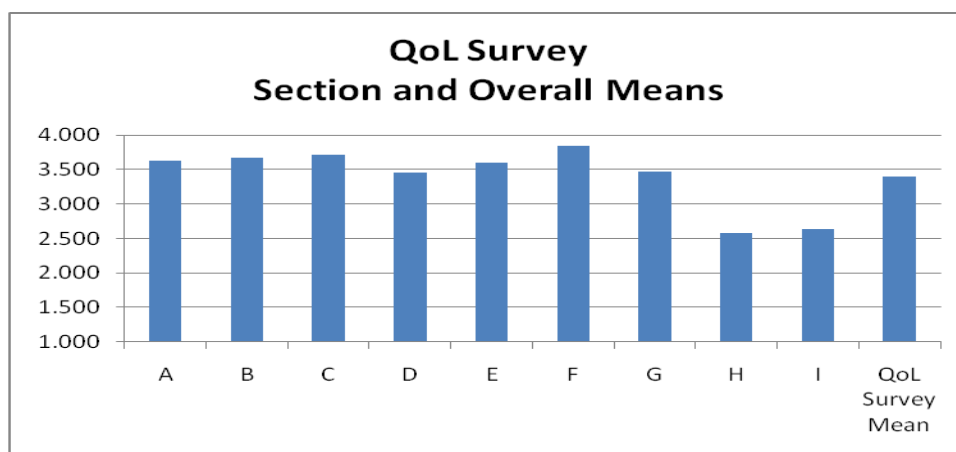


Figure 5.29 The histogram presents Section Means and an overall Mean for the QoL Survey.

The central tendency of the distribution, and the most typical or representative value of the distribution presented through the QoL Survey is the response ‘4’. The overall mean for the entire survey was 3.399. The highest overall mean was section F. Respect. The lowest overall mean score was section H. Activities and Community Integration. Section I. also had a low mean, 2.631, when compared to the survey average. Combined, sections H. and I. had a mean of 2.604, compared to the rest of the survey, sections A. through G., at a mean of 3.627. The home alone group scored particularly low in Sections H and I, with high amounts of 0 = Never and 1 = Rarely responses. It could be speculated based upon comments made by the participants to the researcher, and these means, that overall they have issues surrounding social isolationism and personal relationships. Those who are living alone seem to have particular issues concerning emotional health with regards to opportunities for affection and/or romance, and the roles that they play, or they perceive that they play, in others lives.

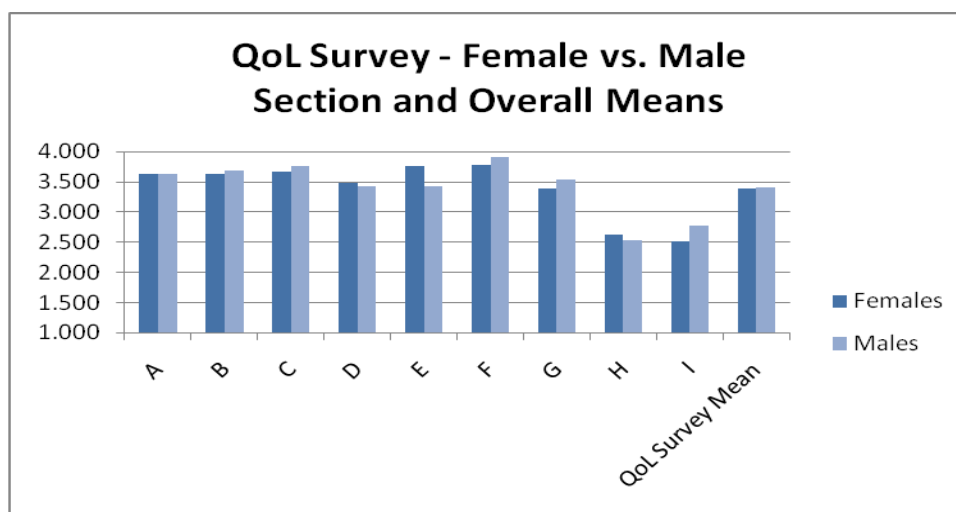


Figure 5.30 Mean scores for female vs. male by section and overall average for QoL Survey.

When examining the sections based upon gender, the results show an overall mean for females of 3.389 while males had an overall mean of 3.407. The most common response in the female/male comparison was 4 – ‘Always’. The section with the largest difference of mean scores, 0.350, was E. Autonomy. In section E., it was E3, “I can go where I want on the spur of the moment”, that males had a particularly low mean of 2.357 when

compared to the female mean of 3.063, a difference of 0.706. E3 had ten out of sixteen females score 3 – Most of the Time or 4 – Always, compared to males who had only five scores of 3 or 4. Overall, the statements with the largest difference in mean were H1 “If I want I can take part in activities in the community” at 0.929 where ten out of the sixteen females scored a 3 or 4 but only seven out of the fourteen men had scores of 3 or 4. I3 “I have opportunities for affection or romance” at 0.955 only had four scores of 3 or 4 out of fourteen females, while males had seven scores of 3 or 4 out of fourteen. On Statement G6 “I consider a _____ staff (fill in program name or type of staff) member my friend” males had a higher mean by 0.798 with eight scores of 3 or 4 out of twelve responses for males, while females had ten scores of 3 or 4 out of fifteen responses. The section with the closest means between females and males was A. Privacy, where the difference was only 0.002. Statement B2, “I get enough to eat”, had the survey’s only perfect mean of 4.000. This means that every participant scored B2 with ‘Always’. The trends of low mean scores between females and males in Sections H and I obviously follow the same low means achieved in the overall survey.

When examining the female/male comparison, three statements were found to be statistically significant. The p-values of D3, E1, and F4 are listed on table 5.10 below. These statements will be discussed further in Section Six Discussion.

Statement	p-value
D3	.010
E1	.010
F4	.020

Table 5.10 P-values of significance in Female vs. Male Section Comparisons.

- D3 I can easily go outdoors if I want.
 E1 I decide when to go to bed and get up.
 F4 People ask before using my things.

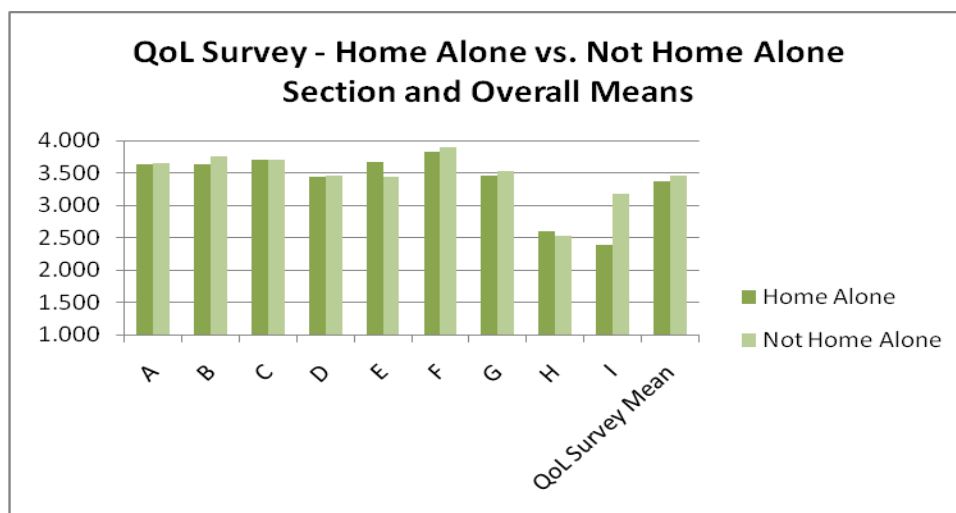


Figure 5.31 Mean scores for Home Alone vs. Not Home Alone by section and with the overall section mean.

When examining the sections based upon Home Alone vs. Not Home Alone, the results show an overall mean for Home Alone of 3.372 while the Not Home Alone group had an overall mean of 3.461. The section with the largest difference of mean scores, 0.788, was I. Personal Relationships. In section I., it was I3, “I have opportunities for affection or romance”, that the Home Alone group had a particularly low mean of 1.000 when compared to the Not Home Alone group mean of 3.111, a difference of 2.111. This indicated that a majority of those home alone scored 1 – Rarely or 0 – Never, as opposed to those not home alone who scored mostly 3 – Most of the Time and 4 - Always. Overall, this made statement I3 in the Home Alone vs. Not Home Alone comparison the largest difference between measured groups in the QoL survey. Statement I2, “I play an important role in people’s lives” had a difference of 0.959 between the Home Alone group and the Not Home Alone Group. The section with the closest means between these two groups was C. Safety and Security, where the difference was only 0.001. There were three statistically significant p-values found within the home alone/not home alone groups with statements I2, I3 and H5 all within the significant range of less than or equal to .05. Table 5.11 outlines statements in the comparison that had p-values of significance. These statements will be further discussed in Section five Discussion. The continuing trend of low mean scores in Section H Activities and Community Integration and Section I Personal Relationships both from the overall survey itself and across group comparisons

indicate possible issues surrounding the emotional health in the elderly at home. Especially in the home alone group.

Statement	p-value
H5	.050
I2	.012
I3	.001

Table 5.11 P-values of significance in Home Alone vs. Not Home Alone Section comparisons.

H5 People outside my home ask for my help or advice.

I2 I play an important role in people's lives.

I3 I have opportunities for affection or romance.

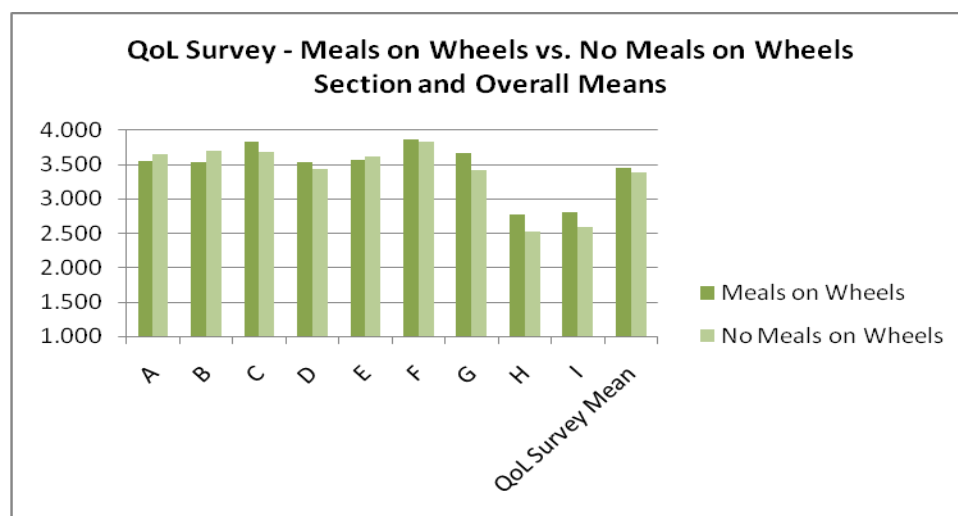


Figure 5.32 Section and overall means for Meals on Wheels group vs. No Meals on Wheels groups.

There were no statistically significant means when examining means in the meals on wheels/no meals on wheels groups. It was interesting to note though that of the six participants who received meals on wheels five were males.

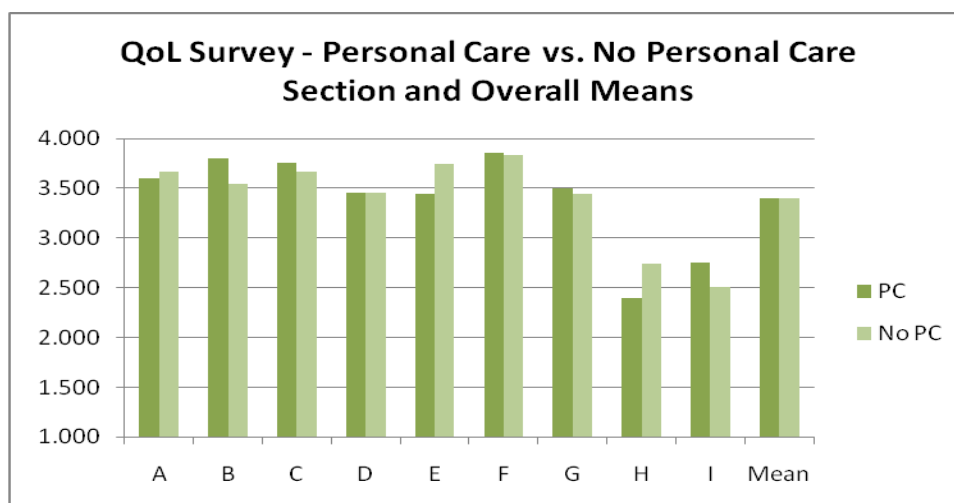


Figure 5.33 Section and overall means for Personal Care vs. No Personal Care groups.

When examining the sections based upon personal care/no personal care, the results show an overall mean for personal care of 3.397 while the no personal care group had an overall mean of 3.400. The section with the largest difference of mean scores, 0.346, was H., Activities and Community Integration with the personal care group mean at 2.392 and the no personal care group at 2.738. The personal care group had a total of 36 scores (out of seventy) of 3 – Most of the Time or 4 – Always. The no personal care group had forty six scores of 3 or 4 (out of eighty). In section H., it was H1, “If I want, I can take part in activities in the community.”, that the personal care group had a particularly low mean of 2.071 when compared to the no personal care group mean of 3.000, a difference of 0.929. This indicates a majority of the personal care group scoring a 2 – Sometimes, while a majority of the personal care group scored 3 – Most of the Time. Statement E3, “I can go where I want on the spur of the moment.” had a difference of 0.839. Eleven out of sixteen from the no personal care group scored a 3 or 4 on E3, while only five out of fourteen from the no personal care group scored a 3 or 4. The section with the closest means between these two groups was D. Comfort and Environment, where the difference was only 0.003. There were four statistically significant p-values found within the personal care/no personal care group with statements B4, D3, E3, and E7 all within the significant range of less than or equal to .05. Table 5.12 outlines statements within the comparison that had p-values of significance. These statements will be further discussed in Section five Discussion.

Statement	p-value
B4	.012
D3	.010
E3	.029
E7	.017

Table 5.12 P-values of significance in Personal Care vs. No Personal Care Section comparisons.

B4 I enjoy mealtimes.

D3 I can easily go outdoors if I want.

E3 I can go where I want on the “spur of the moment.”

E7 I can have a bath or shower as often as I want.

Overall, there were thirteen hundred and eighty responses, from nine different sections, and thirty participants.

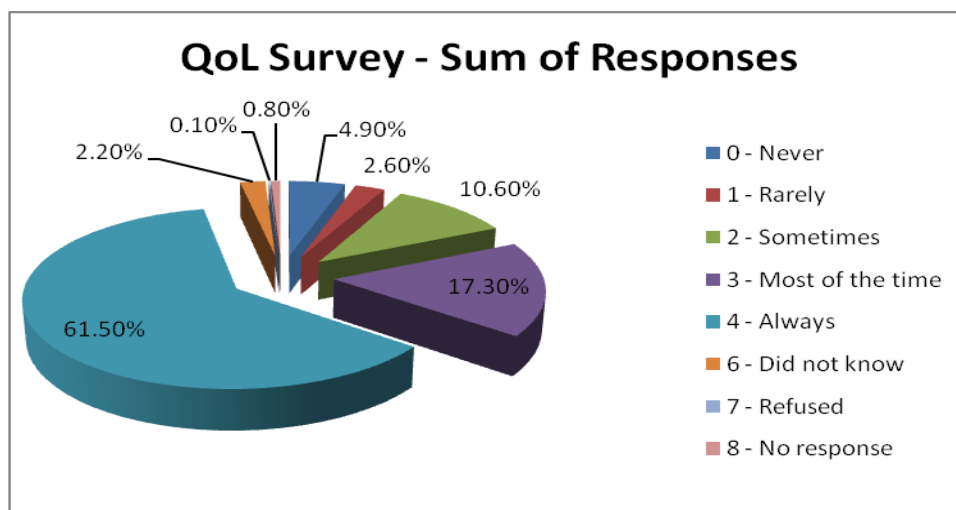


Figure 5.34 Breakdown of the total amount of responses received from participants on the Quality of Life Survey, from zero through to eight.

As the mean response of the participants on the survey was 3.399, one method in looking at measures of association is to find the dispersion of the variables and then their standard deviations. The dispersion of a distribution can provide us with information about how tightly grouped the values in the survey are around the centre of the distribution, or the mean of 3.399 itself. In looking at the range of values we obviously have responses to statements in a range of zero to four, with the ability to also answer 6, 7, or 8. Values 6, 7 and 8 are not scored as they have no numerical value. In looking at the range of distribution, there were 68 responses of '0' - Never, 36 responses of '1' - Rarely, 146 responses of '2' - Sometimes, 239 responses of '3' - Most of the Time, and 849 responses of '4' - Always. Responses '6' - Did Not Know, '7' - Refused, and '8' - No Response, received a total of 42 responses. A precise method of measure of the dispersion around the mean of 3.399 is the variance. This will give a sense of how closely concentrated the set of values one through four are around the mean of 3.399. The variance of the distribution of values from the QoL Survey can give an average of how far, in squared units, the values in the distribution are from the mean of 3.399. By using Microsoft Excel to examine the gathered data, the calculated variance has been determined to be 0.217. By taking the square root of the variance, the standard deviation of 0.466 is determined. By this measure it can be concluded with reasonable certainty that:

1. Approximately 68% of the values of the QoL Survey will fall within one standard deviation (0.466) of the mean (3.399). This yields a range of 2.933 to 3.865.
2. Approximately 95% of the values of the QoL Survey will fall within two standard deviations of the mean. This yields a range of 2.467 to 4.000.
3. Approximately 99% of the values of the QoL Survey will fall within three standard deviations of the mean. This yields a range of 2.001 to 4.000.

6.0 **Discussion**

Key drivers of this thesis, well supported by the various literature and reviewed research throughout the chapters, is that there is a dearth of research of the elderly using QoL assessment instruments in New Zealand and the need for a uniform method of measuring and following up with QoL issues in elderly living in their homes. This study did not assess QoL issues of the elderly living in residential care. This study set out to demonstrate the ability of the interRAI QoL Survey as a self-assessment tool which could be used to elucidate these QoL issues which the elderly may or may not be living with on a daily basis. Despite limitations of the study, such as geography or a lack of a follow up QoL Survey, through supporting research and data gathered from the QoL Survey itself, the aim and objectives of the study have been achieved.

6.1 Research Aim

The overall research aim is to evaluate the adequacy of the interRAI Quality of Life survey in assessing the QoL issues and needs of the elderly living in their own homes in the community with some sort of publicly funded health care, social or community support such as meals on wheels or personal care, for the purpose of demonstrating the value of it as a useful tool within New Zealand.

6.2 Research Objectives

- Objective 1 - To review the management and application of quality of life indicators for the elderly.
- Objective 2 – To understand the pressures which an ageing population places on public policy.
- Objective 3 - To consider how quality of life measures can best be applied alongside interRAI in New Zealand.

6.3 Background to the Problem

New Zealand currently has no method of uniformly measuring the QoL of the elderly living in their own homes. Statistics New Zealand show that by 2051 the number of people aged 65 years and older in New Zealand is projected to exceed 1.33 million, or approximately 25% of the population. As the population of New Zealand continues to age, so will the number of elderly living in their own homes.

The pressures which an ageing population places on public policy is described in the literature of this study. After a successful trial of the interRAI – Home Care assessment tool in five selected DHBs in 2006, the New Zealand MoH decided to roll out the tool nationwide. Although the MDS – HC does have domains which touch upon certain issues of quality of life, there is no specific domain, statement or question that deals expressly with this important issue.

In April 2008, Dr. Morris presented to an interRAI conference in Barcelona, Spain, his new concept of a self assessed Quality of Life (QoL) assessment tool which would focus on the person's own perspective of their life and care experiences in the context of the care setting in which they live (interRAI, 2008). Its functional ability as a self assessment tool, when coupled with the Home Care tool, will enable for a more complete, or holistic, view of the client through a self reported survey which will “focus on the person's own perceptions of their quality of life, in the context of the care setting in which they live” (interrai.org, 2008). It is the first tool within interRAI which is centred on the client's point of view. Dr. Brigitte Larkins of the Ministry of Health, and the project head for the implementation of interRAI – HC throughout the DHBs, realized the potential that the QoL Survey had to impact the lives of the elderly in New Zealand and suggested this as a suitable Thesis project. The ability to assist those elderly who are living in their own homes with their quality of life could greatly aid them in remaining in those homes and delay any necessary move into a rest home or retirement home.

Objective three, to consider how quality of life measures can best be applied alongside interRAI, is an important consideration of how the QoL survey could be best utilised within the framework of the Health of Older Persons Strategy and specifically the DHBs. The ability for the QoL Survey to work as a complement to the interRAI – Home Care assessment can only be proven through a wider trial through the DHBs. By using both tools in combination, there will be a more accurate view of the Home Care tool which encompasses health issues, and the QoL Survey tool which well encompasses quality of life issues. In this manner, we get a more holistic approach to the care of the elderly living in their own homes.

Studies vary, but it has been shown to be cost effective to provide the elderly with home care options to assist them to live in their own homes, as opposed to living in residential retirement homes/long term care. This issue was addressed in papers by David C. Grabowski (Grabowski, 2006) on the cost effectiveness of non-institutional long term care services, in an early paper by Susan L. Hughes (Hughes et al, 1991) at the Department of Veterans Affairs, and also by scrutiny of the Arizona Long-Term Care System (Weissert et al, 1997). In New Zealand, one projected change is an increase in the percentage of households without children living in them, which would partially be due to an increase in the number of elderly living in their own homes (Dunstan & Thomson, 2006).

One important aspect that is lacking from current support systems in New Zealand is a uniform system of measurement of the QoL of the elderly living in their homes. Currently, New Zealand is not able to gauge the QoL of those elderly, and therefore problems may or may not be pervasive. With studies and examples like those from Grabowski (2006), Hughes (1991), and the Arizona Long Term Care System (Weissert, 1997), and the cost savings benefit that has been shown to be derived from implementing systems to keep the elderly living in their own homes, New Zealand could not only lessen the impact of future fiscal issues but also better manage the QoL issues of said elderly.

In examining objective one, reviewing the management and application of quality of life indicators for the elderly, one aspect that was highlighted though the research was the lack of an indicator for emotional problems which the elderly may be facing in their homes. Though the interRAI – HC assessment does have sections and domains which deal with signs and symptoms of depression, it is from the viewpoint of the assessor. Through the self-assessed quality of life survey, and by examining the data, that the health of the elderly living at home is being well looked after, but their emotional health is showing signs of needing assistance.

6.3.1 Predictors of Quality of Life

Throughout the research study from participant interviews and data, many issues of significance were found which will be further expounded upon in this next section. These issues were discovered in extended descriptive statistics through group studies and overall studies, but also through discussions which the participants freely had while self assessing their QoL. These issues and some accompanying data are presented for each group examined.

6.3.1.1 Section A. Privacy

In the case of Privacy issues, women seemed to feel less confident than men that their information was kept private. One problem which bereft spouses spoke about to the researcher was the fact that they had to do household duties which they were unfamiliar with. Two widowers spoke about how it was their husbands who used to deal with the duties of paying bills, dealing with insurance, etc. and they bore an amount of uncertainty regarding having to take on issues which dealt with these private issues. There may be an opportunity here for educational opportunities for this group, which could be identified and follow through on. Although these issues may not at first glance seem to have a place in Privacy, the issue was brought up on three occasions during this section. Indicating that to the participants, the process of paying bills and dealing with insurance was an issue they considered to be associated with privacy. The issue of what was done with

privacy information once it left the persons control was also a predictor of QoL. There was much conversation about this, although in the end scores were still high, six of the participants responded by saying “I don’t know”.

6.3.1.2 Section B Food and Meals

In viewing predictors of quality of life for Section B. Food and Meals, one note of importance was the fact that five out of the six participants who were receiving meals on wheels were males. They did not have anybody to cook for them and either had to cook their own meals or rely upon meals on wheels. Again, bereft spouses had to deal with household duties that had previously been the domain of their spouse. Although they are different household tasks, both males and females may need extra support for some tasks when they have been widowed.

6.3.1.3 Section C Safety and Security

It was clear during these interviews that almost universally, participants had family and friends that they trusted and felt safe around and with. There was a lower amount of safety and security when they were alone, but all scores were close to the “Most of the Time’ to ‘Always’ in range. Overall, this section did not produce any problems or predictors of QoL in this study.

6.3.1.4 Section D. Comfort and Environment

Statement D4, “I tend to be happier than most other people” brought about much conversation and, when looking at the data, low mean scores closely aligned with ‘Sometimes’ to ‘Most of the Time’. It could be explained that the low scores were a result of confusion or dislike of the statement itself, but it could also be a cause of concern about the possibility of a large segment of the elderly population who have issues around basic happiness and is something which should be examined further. Statistically Significant data were discovered when looking into the personal care/no personal groups

for D3, “I can easily go outdoors if I want”, as the personal care group had issues with this. D3 was also found to be an issue in the female/male comparison, with statistically significant data found. Several of the men interviewed had physical or health issues which would have prevented them from easily being able to go outdoors. The issue of being able to easily get outside of one’s home then could be a predictor of QoL which will need to be followed up further in a DHB trial.

Section 6.3.1.5

Section E. Autonomy

The Autonomy section had low scores throughout all comparisons when looking at E3, “I can go where I want on the spur of the moment”. When looking back at the possible issues which the elderly may have in being able to easily get outside of their homes, E3 continues a possible trend of isolation of the elderly in their homes. Statistically significant data was found when looking into the female/male comparison for E1 “I decide when to go to bed and when to get up”. If men were finding it difficult to get outside of their homes, following a continuing trend of possible isolation if they need to wait for a carer to help them get out of bed. When looking into the personal care/no personal care group, there continued to be a trend of isolation with statistically significant data from E3, along with E7 “I can have a bath or shower as often as I want’. It makes sense that if a participant is having issues with getting in and out of bed, that they might also have issues with taking a shower as often as they liked.

Section 6.3.1.6

Section F. Respect

This section has high marks across all comparison groups. Although on the female/male comparison statement F4 “People ask before using my things” was found to be statistically significant, there were no overriding trends or indicators found. With regards to F4, many of the female participants remarked that the cleaners knew where the cleaning products, vacuums, etc. were and didn’t have to ask to use them. It did not appear to be an issue with which the females were troubled by.

Section 6.3.1.7

Section G. Worker Responsiveness

Low scores were achieved on statement G6 “I consider a _____ staff to be a friend”, for females. There were several comments regarding the fact that the participants did not necessarily consider the home workers to be friends, but perhaps acquaintances. Each participant was grateful for their assistance but didn’t necessarily see this as a QoL issue but perhaps more of a fact of life.

Section 6.3.1.8 Section H. Activities and Community Integration

Section H, along with Section I, both had trends of low scores across a majority of the groups and statements. Statement H5 “People outside of my home ask for my help or advice”, scored many responses of ‘Rarely’ to ‘Sometimes’. Females scored much higher on H1 “If I want I can take part in activities in the community”. This again follows a trend of isolation in males. It was in the home alone group that very low scores were seen on statement H5 “People outside my home ask for my help or advice”. This Section had overall the lowest scores of any section. This could indicate an overall predictor of QoL in activities and social integration.

Section 6.3.1.9

Section I. Personal Relationships

Personal Relationships, as with the previous section, had very low scores when compared to other sections. Particularly low was I3 “I have opportunities for affection or romance”. Many of the participants had a difficult time separating what they saw as two distinctly different concepts ‘affection’ and ‘romance’. When looking into the female/male comparison the female group scored much lower. This could be due to the fact that there are more females in the elderly population. But generally the overall view throughout this section, with the exception of I4, “I have people I can count on”, were scores aligning more closely with ‘Sometimes’. When looking into the home alone/not home alone comparison though, we begin to see possible issues with social isolation again as I2, “I play an important role I people’s lives’ and I3 both had very low scores for the home

alone group when compared to the not home alone group. Both were found to be statistically significant. Throughout the comparisons, when looking at the ‘big picture’ it becomes clear that there are a number of participants in this study who have issues with social isolation and possibly unfronted emotional issues which should be examined further.

6.4 Strengths and Limitations of the QoL Survey.

A major limitation of the QoL Survey study was the sample size of only thirty participants. This was because of the difficulties in recruiting participants through the CDHB. A second limitation of the study was that the participants were only recruited locally from the greater Christchurch area. Hence there may be local issues which cannot be extrapolated and generalized onto the larger New Zealand population. A third limitation was the lack of social demographic information about the participants. This meant that the researcher was unable to pursue any further analysis other than female/male, meals on wheels/no meals on wheels, etc.

A strength of the QoL Survey study was the overall setup of the study itself and the roll of the researcher. Strict adherence to researcher rolls to avoid any semblance of researcher bias was followed. The information sheet was read word for word, informed consent forms filled out and signed, and participants informed that their answers to statements on the QoL Survey were their views alone. No input was to be solicited and none was given by the researcher in this regard.

6.5 Implications and Recommendations for Future Policy and Research

The concept of a self assessed quality of life instrument as a tool to assist in the measurement of quality of life in New Zealand is one which is backed up by previous policy already in place. The New Zealand Positive Ageing Strategy has set out guidelines for the care and welfare of older people. The Health of Older People Strategy further sets out strategies for the short and long term care of the elderly in New Zealand. The Primary

aim of the Health of Older People Strategy is to develop an integrated approach to health and disability support services that is responsive to older people's varied and changing needs. Both being living documents, it is easy to extrapolate the need for a tool to measure the QoL of the elderly living in their own homes in New Zealand. With higher numbers of the elderly living into their seventies, eighties, and their nineties in age, higher numbers of homes without children, and an inextricably linked QoL alongside home ownership, it is imperative that New Zealand acts to secure a pathway to the measurement of QoL with the implementation of the interRAI QoL Survey.

As acknowledged earlier, the interRAI – Home Care tool has many strengths. It addresses issues such as the inter-relationship between health and disability, the problems of information duplication and omission in the assessment of older people, and the lack of consistency across settings, disciplines, and regions (Gilhooley, 2008). These strengths were primary reasons for the successful trial of this tool in five DHBs across New Zealand and for its full implementation across the DHB starting in 2008. It does have a limitation though of the lack of self assessment and the lack of ability to measure quality of life. With the implementation of the QoL Survey in a limited trial through the DHB, the full potential of this tool can be truly viewed.

For a trial of the QoL Survey to be successful, certain issues would need to be acknowledged, confronted, and carried out.

- First and most importantly, it is imperative that there be a follow up visit to the initial QoL interview. Through a follow up visit the researchers can examine QoL measures which were implemented to assist with those issues which the participant viewed as detrimental to his/her QoL.
- Second, the QoL Survey needs to become a permanent follow up to the interRAI – Home Care Assessment. An appointment to be assessed through the QoL Survey, no longer than six weeks apart from the MDS – HC assessment, needs to occur. This should happen for every MDS – HC assessment during the trial period.
- Third, a researcher or team of researchers needs to be able to work within the

confines of the interRAI team(s) through the DHB for complete cooperation and exchange of data and information to suitably transpire. Without the complete cooperation of the DHB through teamwork and data/information exchange, a satisfying result will be very difficult to attain.

- Fourth, as the QoL Survey has no specific section or statement(s) regarding Maori life and/or Whanau, consideration should be given to making the QoL more New Zealand specific regarding cultural identity and needs of Maori.
- Fifth, the scoring system in place within the confines of the QoL Survey is different than the interRAI – HC assessment. If the scoring system in place for the QoL Survey was modified to fit within the framework of the interRAI – HC assessment, the results from one would be more easily interpreted and compliment the other.
- Sixth, statements D4 and I3 should be scrutinized for possible change as both caused much confusion amongst participants. D4, “I tend to be happier than most other people”, was viewed as a very subjective question. Indeed, it is difficult to ascertain another person’s level of happiness, or what they consider to be happiness. The subjectivity of the statement may have caused much variation in participant responses. Statement I3, “I have opportunities for affection or romance”, also caused much confusion amongst participants. The inclusion of ‘affection’ and ‘romance’ in the same statement showed be analyzed and perhaps separated into two different statements.
- Seventh, many of the participants found the font of the survey to be too small. In order for them to be able to more effectively self-assess their own QoL, a larger font should be applied to the survey template. The font and size used for the survey was Times New Roman 12.
- Eighth, Section D. should have a statement added regarding whether or not a participant would like to continue living in their home.
- Ninth, a tick box should be added so that it is possible to find out who filled out the form, the participant or the researcher.
- Tenth, discussion should occur regarding adding a statement to Section C. concerning elder abuse. Or, perhaps Statement C4 “I feel safe around my family

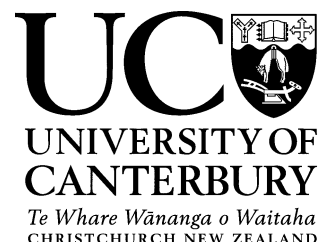
and friends”, or C2 “I feel safe around those who provide me with support and care” could be modified to add information regarding elder abuse.

Appendix A: Informed consent for initial contact by QoL assessor

Health Sciences Centre

Tel: +64 3 366 7001, Fax: + 64 3 364 2490

Email: healthsciences@canterbury.ac.nz



INFORMED CONSENT FORM

For participation in the study
InterRAI Quality of Life Survey

Project Description

The Quality of Life Survey is a Masters Thesis study being performed by Christopher P. Brandt from the University of Canterbury. The survey itself is intended to be a follow-up to the InterRAI Assessment which you have recently been a part of. The main idea of this survey is to gain an overall assessment of your (the client) self reported quality of life. You (the client) will be presented a series of questions ranging from Privacy, Safety, Autonomy, Personal Relationships and more. If you would like to participate, more detailed information concerning the study will be presented to you upon meeting with Mr. Brandt.

Informed Consent (Please check a box)

☐

I, _____, give permission for my name and telephone number to be given to Christopher P. Brandt for the purpose of his contacting me to participate in the InterRAI Quality of Life Survey.

☐

I am not interested in participating in the InterRAI Quality of Life Survey. Please do not give out my contact information.

Signature
(participant): _____

Date: _____

Telephone Number: _____

Appendix B: Informed consent for participation in QoL survey study

Health Sciences Centre

Tel: +64 3 366 7001, Fax: + 64 3 364 2490

Email: healthsciences@canterbury.ac.nz



INFORMED CONSENT FORM

For participation in the study

InterRAI Quality of Life Survey

Please tick to confirm

- ☐ I have read and I understand the attached information sheet for participating in the interRAI Quality of Life survey. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.
- ☐ I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.
- ☐ I understand that taking part in this study is voluntary and that I may withdraw from the study at any time. If I withdraw from the study, I understand that all information given will be also be withdrawn from the study. I fully understand that there will be no adverse effects or change in current services by any withdrawal from this study.
- ☐ I have had time to consider whether to take part.
- ☐ I know who to contact if I have any concerns in regard to participating in this study.
- ☐ I understand that the information gathered from this survey may be passed along to relevant health care professionals (Age Concern) for the purpose of increasing my quality of life.
- ☐ I consent to the use of my data for future related studies, which have been given approval from a Health & Disability Ethics Committee. Said future related studies have not been granted approval from the Health and Disability Ethics Committee.
- ☐ I know who to contact if I have any questions about the study.

* I wish to receive a brief summary of the study results Yes / No (Please circle one)

Please post the summary to: (please write your postal address)_____.

I _____ (please print your full name) hereby consent to take part in this study.

Signature
(participant): _____ **Date:** _____
Telephone Number: _____

Project explained by: Christopher P. Brandt
Signature: _____

Contact Details

Researcher: Christopher P. Brandt, MHealSc student, University of Canterbury
Email: ibwaterman@hotmail.com
Ph: 03 366 7001 ext 8691 (Health Science Centre, University of Canterbury)
Cell Ph: 021 112 6901 or _____

Supervisors:

Assoc. Professor Ray Kirk, Ph.D., Director Health Science Centre, Univ. of Canterbury
Assoc. Professor Pauline Barnett, Ph.D., Health Science Centre, Univ. of Canterbury
Brigitte Larkins, Ph.D., Senior Project Manager, Ministry of Health

Ph: 03 366 7001 ext 8691 (Health Science Centre, University of Canterbury)
Email: healthsciences@canterbury.ac.nz

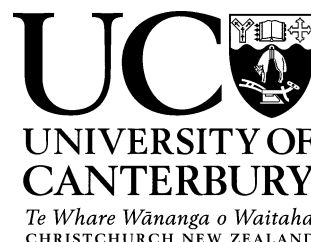
Please do not hesitate to contact Christopher or his supervisors at any time if you have any questions or wish to discuss your participation

Appendix C: Information sheet for QoL survey study

Health Sciences Centre

Tel: +64 3 366 7001, Fax: + 64 3 364 2490

Email: healthsciences@canterbury.ac.nz



Information Sheet for participants on the study of interRAI Quality of Life Survey

Dear Sir or Madam,

Thank you very much for your time in reading this information sheet. You are invited to take part in a Master's dissertation research study. This study will be looking into the quality of life of elderly New Zealanders who are receiving some sort of public service, such as regular visits by Nurse Maude, physiotherapy, meals on wheels, etc. The survey will take place in participant's homes.

This information sheet will explain why this study is being done, and what will be required of participants as well as how this study will be carried out. This information will help you to decide whether you wish to take part in this study. If necessary, you might ask your friends, whanau/ family members or support people to help you make up your mind.

After you have been seen by an InterRAI Assessor, he or she will ask whether or not you are interested in participating in this Quality of Life Survey, and accordingly, whether you would sign an Informed Consent for your contact information to be passed along so the researcher can contact you. Within thirty days, a time will be set for the researcher to meet with you at your home so that questions can be answered prior to signing a second Informed Consent and starting the survey.

Why is this study being done?

InterRAI is a collaborative network of researchers in over 30 countries committed to improving health care for persons who are elderly, frail, or disabled. Our goal is to promote evidence based clinical practice and policy decisions through the collection and interpretation of high quality data about the characteristics and outcomes of persons served across a variety of health and social services settings.

InterRAI researchers have recently made important first steps toward developing a new dimension to its assessment systems, focused on the persons' own perspective of their life and care experiences. Existing InterRAI assessment instruments are based on the assessors' evaluation of the person's problems, performance and perceptions. The proposed new assessment instrument will focus on the persons' own perception of their quality of life, in the context of the care setting in which they live.

The assessments will be completed by the person directly, or through interview.

What are the aims of this study?

- To directly link to the conventional InterRAI assessment systems, such as the InterRAI Home Care, with results from the Quality of Life Survey.
- To analyse the relationship between the InterRAI assessment and the Quality of Life Survey.
- To analyze whether or not the level of care correlates with InterRAI data or is independent of level of care.
- To validate the Quality of Life Survey for use within New Zealand
- To see that quality of life indicators are thoroughly analyzed and followed through.

Who are invited to take part in this study?

Participants of InterRAI Home Care Assessment who have scores of two or less on the Cognitive Performance Scale.

What are the roles of participants?

1. You will be asked for one interview by a principal researcher (Christopher P. Brandt). This interview may take approximately 30 to 60 minutes. During the interview, an explanation of the survey will be given and general questions will be asked relating to the survey. The researcher will answer any questions that you may have.

➤ ***Where will the interview be held?***

At the home of the participant

➤ ***When?***

A suitable time will be individually arranged with you.

➤ ***Who will be interviewed?***

As the survey is querying the self reported quality of life, ideally the participant should be interviewed alone by the researcher.

2. **A Quality of Life Survey** will be given to you. This survey can be completed by the participant alone or via a one on one interview by the researcher.

➤ ***About the survey:***

The survey, **InterRAI Self Reported Home Care/Community Living Quality of Life Survey**, will be used in this study, although it will be modified to fit New Zealand standards and needs. The survey comprises nine sections of quality of life indicators of which each section has between four to seven questions.

➤ ***Who will fill in the survey?***

The participant may fill out the survey alone, or via an interview with the researcher.

What are the benefits or risks of this study?

As a participant you may benefit from feedback regarding the collected data from the survey. The feedback will be available to you on your request. In addition, a brief summary of the study results will be posted to you when the project is completed if you

check this option on the consent form. Recommendations will be made in the completed Thesis which will assist those future participants with their own quality of life.

It is expected that there will be no risks associated with your participation, however, if the completion of the survey raises issues or anxieties for you which you would like to discuss please contact the study supervisors or the researcher.

With your permission, data from this study may be used in future related studies, which have been given approval from a Health & Disability Ethics Committee. Said future related studies have not yet been given any approval from the Health and Disability Ethics Committee.

If during the course of this study you become distressed or feel like your quality of life is lacking in any respect and that you wish change to occur, information and contacts will be provided about the support group 'Age Concern'.

Will any payments be made to participants?

No. There will be no payment made from participating in this study.

Who can support the participants if there are any concerns?

The principal researcher, Christopher P. Brandt, can be contacted if there are any concerns/ questions. If needed, the supervisors of this research study can also be contacted (please refer the contact details below).

How much information of the participants will the researcher access?

The principal researcher will have access to information from the interview, the survey, and the MDS – HC assessment.

How will the confidentiality be kept?

The collected survey will be stored within the principal researcher's locked box. The data will be stored on the principal researcher's password-protected personal computer. The data will be stored securely for 10 years at the Health Sciences Centre, University of Canterbury. As this is a quality of life study though, particular participant issues which arise may be referred to health care professionals for further assistance.

Participation is totally voluntary. At any stage, the participants can ask any questions, withdraw their consent or refuse any part of the study.

What happens if I decide not to participate or to withdraw my participation during the study?

You may at any time decide either not to participate or to withdraw from the study. There will no adverse effects from this decision and there will be no changes to any current services you are receiving. If you withdraw from the study, any information gathered from the study will also be withdrawn.

Who is supervising this study?

This study is being undertaken at the University of Canterbury with assistance by the Canterbury District Health Board and the Ministry of Health.

Supervisors:

Ray Kirk, Ph.D., Director, Health Sciences Centre, University of Canterbury

Pauline Barnett, Ph.D., Health Science Centre, University of Canterbury

Brigette Larkins, Ph.D. Senior Project Director, Ministry of Health

Thank you very much for your time in considering participation in this study. Please do not hesitate to contact either the principal researcher or her supervisors for further information.

Principal Researcher:

Christopher P. Brandt – 021 112 6901 Personal Mobile

Email: ibwaterman@hotmail.com

Telephone: 03 364 7628 (Health Science Centre)

This study has been given approval by the University of Canterbury Human Ethics Committee, the Ministry of Health, and the Canterbury District Health Board. If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone (NZ wide): 0800 555 050

Free Fax (NZ wide): 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide): advocacy@hdc.org.nz

Appendix D: Quality of Life Survey

InterRAI Self-Reported Home Care/Community Living Quality of Life Survey[©]

Date of Interview: ____ / ____ / ____
 DD MM YYYY

Interviewer Name: _____

Interviewee Name: _____

Greetings and thank you for your time. I am going to ask you about your quality of life. We at interRAI want to determine how well _____ (name of programme) is providing service for you. There are no right or wrong answers as this survey concerns what life is like for you.

USE THESE ADDITIONAL CODES AS NECESSARY:

*6=Did not know, 7= Refused, 8 = No response or cannot be coded from response
(write down what is said)*

A. Privacy

First, I'd like to talk with you about privacy.

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always

- _____ 1. **I can be alone when I wish.**
- _____ 2. **I can have a private conversation when I wish.**
- _____ 3. **My privacy is respected when people care for me.**
- _____ 4. **My personal information is kept private.**

B. Food/Meals

The items that follow are about your meals.

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always

- _____ 1. **I get my favourite foods.**
- _____ 2. **I get enough to eat.**

_____ 3. I have enough variety in my meals.

_____ 4. I enjoy mealtimes.

C. Safety/Security

Now let's talk about safety.

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always

_____ 1. I feel safe when I am alone.

_____ 2. I feel safe around those who provide me with support and care.

_____ 3. If I need help right away, I can get it.

_____ 4. I feel safe around my family and friends.

_____ 5. I feel my possessions are safe.

D. Comfort and Environment

The items that follow focus on the decisions you make about day-to-day activities.

[Refers to D and E below]

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always

_____ 1. I get the services I need.

_____ 2. I would recommend this program to others.

_____ 3. I can easily go outdoors if I want.

_____ 4. I tend to be happier than most other people.

_____ 5. My home is as clean as I would like.

E. Autonomy

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always

_____ 1. I decide when to go to bed and get up.

- _____ 2. I decide how to spend my time.
- _____ 3. I can go where I want on the “spur of the moment.”
- _____ 4. I control who comes into my home.
- _____ 5. I decide how my money is spent.
- _____ 6. I live where I want.
- _____ 7. I can have a bath or shower as often as I want.

F. Respect

Now I'd like to discuss how you feel about the people who provide your care and supports. [Refers to F and G]

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always

- _____ 1. I can express my opinion without fear of consequences.
- _____ 2. I am treated with respect by the people involved in my support and care.
- _____ 3. _____ staff (fill in program name or type of staff) respect what I like and dislike.
- _____ 4. People ask before using my things.
- _____ 5. _____ staff (fill in program name or type of staff) take advantage of me.

G. Worker Responsiveness

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always

- _____ 1. My services are delivered when I want them.
- _____ 2. The care and support I get help me live my life the way I want.
- _____ 3. _____ staff (fill in program name or type of staff) act on my suggestions.
- _____ 4. I can get the health services I need.
- _____ 5. _____ staff (fill in program name/type of staff) talk to me about how to meet my needs.
- _____ 6. I consider a _____ staff (fill in program name/type of staff) member my friend.

H. Activities and Community Integration

Now, let's look at how you feel about activities.

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always

- _____ 1. If I want, I can take part in activities in the community.
- _____ 2. I can do activities that are important to me.
- _____ 3. If I want, I can participate in religious activities that have meaning to me.
- _____ 4. I belong to a group that sees me as a valued member.
- _____ 5. People outside my home ask for my help or advice.

I. Personal Relationships

Finally, we will talk about your relationships with others.

For each statement please answer with one of the following choices:

0) Never 1) Rarely 2) Sometimes 3) Most of the time 4) Always

- _____ 1. I have people who want to do things together with me.
- _____ 2. I play an important role in people's lives.
- _____ 3. I have opportunities for affection or romance.
- _____ 4. I have people I can count on.
- _____ 5. People know the story of my life.

This ends the survey on your quality of life. On behalf of interRAI, I thank you for your participation.

For interRAI interviewer Notes:

©interRAI 2008 [2008, 2009]



Appendix E: interRAI – Home Care Assessment

Name of Client _____

NHI Number _____

4	TIME SINCE LAST HOSPITAL STAY	Time since discharge from last inpatient setting (Code for most recent instance in LAST 180 DAYS) 0. Presently in hospital 1. No hospitalization within 180 days 2. Within last week 3. Within 8 to 14 days 4. Within 15 to 30 days 5. More than 30 days ago	<input type="checkbox"/>
5	WHERE LIVED AT TIME OF REFERRAL	1. Private home/apt. with no home care services 2. Private home/apt. with home care services 3. Board and care/assisted living/group home 4. Residential care facility 5. Other	<input type="checkbox"/>
6	WHO LIVED WITH AT REFERRAL	1. Lived alone 2. Lived with spouse only 3. Lived with spouse and other(s) 4. Lived with child (not spouse) 5. Lived with other(s) (not spouse or children) 6. Lived in group setting with non-relative(s)	<input type="checkbox"/>
7	PRIOR RESIDENTIAL CARE FACILITY PLACEMENT	Resided in a residential care facility at anytime during 5 YEARS prior to case opening 0. No 1. Yes	<input type="checkbox"/>
8	RESIDENTIAL HISTORY	Moved to current residence within last two years. 0. No 1. Yes	<input type="checkbox"/>

SECTION A. ASSESSMENT INFORMATION			
1	ASSESSMENT REFERENCE DATE	Date of assessment Day: <input type="text"/> <input type="text"/> Month: <input type="text"/> <input type="text"/> Year: <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
2	REASON FOR ASSESSMENT	Type of assessment 1. Initial assessment 2. Follow-up assessment 3. Routine assessment at fixed intervals 4. Review within 30-day period prior to discharge from the programme 5. Review at return from hospital 6. Change in status 7. Discharge/transfer from service 8. Other	<input type="checkbox"/>

SECTION B. COGNITIVE PATTERNS			
1	MEMORY RECALL ABILITY	(Code for recall of what was learned or known) 0. Memory OK 1. Memory problem a. Short-term memory OK—seems/appears to recall after 5 minutes b. Procedural memory OK—can perform all or almost all steps in a multitask sequence without cues for initiation	<input type="checkbox"/> <input type="checkbox"/>
2	COGNITIVE SKILLS FOR DAILY DECISION-MAKING	a. How well client made decisions about organizing the day (e.g. when to get up or have meals, which clothes to wear or activities to do) 0. INDEPENDENT—Decisions consistent/reasonable/safe 1. MODIFIED INDEPENDENCE—Some difficulty in new situations only 2. MINIMALLY IMPAIRED—In specific situations, decisions become poor or unsafe and cues/supervision necessary at those times 3. MODERATELY IMPAIRED—Decisions consistently poor or unsafe, cues/supervision required at all times 4. SEVERELY IMPAIRED—Never/rarely made decisions b. Worsening of decision making as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days) 0. No 1. Yes	<input type="checkbox"/> <input type="checkbox"/>

3	INDICATORS OF DELIRIUM	a. Sudden or new onset/change in mental function over LAST 7 DAYS (including ability to pay attention, awareness of surroundings, being coherent, unpredictable variation over course of day) 0. No 1. Yes b. In the LAST 90 DAYS (or since last assessment if less than 90 days), client has become agitated or disoriented such that his or her safety is endangered or client requires protection by others 0. No 1. Yes	<input type="checkbox"/> <input type="checkbox"/>
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SECTION C. COMMUNICATION/HEARING PATTERNS			
1	HEARING	(With hearing aid if used) 0. HEARS ADEQUATELY—Normal talk, TV, phone, doorbell 1. MINIMAL DIFFICULTY—When not in quiet setting 2. HEARS IN SPECIAL SITUATIONS ONLY—Speaker has to adjust tonal quality and speak distinctly 3. HIGHLY IMPAIRED—Absence of useful hearing	<input type="checkbox"/>
2	MAKING SELF UNDERSTOOD (Expression)	(Expressing information content—however able) 0. UNDERSTOOD—Expresses ideas without difficulty 1. USUALLY UNDERSTOOD—Difficulty finding words or finishing thoughts BUT if given time, little or no prompting required 2. OFTEN UNDERSTOOD—Difficulty finding words or finishing thoughts, prompting usually required 3. SOMETIMES UNDERSTOOD—Ability is limited to making concrete requests 4. RARELY/NEVER UNDERSTOOD	<input type="checkbox"/>
3	ABILITY TO UNDERSTAND OTHERS (Comprehension)	(Understands verbal information—however able) 0. UNDERSTANDS—Clear comprehension 1. USUALLY UNDERSTANDS—Misses some part/intent of message, BUT comprehends most conversation with little or no prompting 2. OFTEN UNDERSTANDS—Misses some part/intent of message; with prompting can often comprehend conversation 3. SOMETIMES UNDERSTANDS—Responds adequately to simple, direct communication 4. RARELY/NEVER UNDERSTANDS	<input type="checkbox"/>
4	COMMUNICATION DECLINE	Worsening in communication (making self understood or understanding others) as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days) 0. No 1. Yes	<input type="checkbox"/>

SECTION D. VISION PATTERNS			
1	VISION	(Ability to see in adequate light and with glasses if used) 0. ADEQUATE—Sees fine detail, including regular print in newspapers/books 1. IMPAIRED—Sees large print, but no regular print in newspapers/books 2. MODERATELY IMPAIRED—Limited vision; not able to see newspaper headlines, but can identify objects 3. HIGHLY IMPAIRED—Object identification in question, but eyes appear to follow objects 4. SEVERELY IMPAIRED—No vision or sees only light, colours, or shapes; eyes do not appear to follow objects	<input type="checkbox"/>
2	VISUAL LIMITATION/DIFFICULTIES	Saw halos or rings around lights, curtains over eyes, or flashes of lights 0. No 1. Yes	<input type="checkbox"/>

Name of Client _____

NHI Number _____

3	VISION DECLINE	Worsening of vision as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days) 0. No 1. Yes	<input type="checkbox"/>
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SECTION E. MOOD AND BEHAVIOUR PATTERNS

1	INDICATORS OF DEPRESSION, ANXIETY, SAD MOOD	<i>(Code for observed indicators irrespective of the assumed cause)</i> 0. Indicator not exhibited in last 3 days 1. Exhibited 1–2 of last 3 days 2. Exhibited on each of last 3 days a. A FEELING OF SADNESS OR BEING DEPRESSED , that life is not worth living, that nothing matters, that he or she is of no use to anyone or would rather be dead b. PERSISTENT ANGER WITH SELF OR OTHERS —e.g. easily annoyed, anger at care received c. EXPRESSIONS OF WHAT APPEAR TO BE UNREALISTIC FEARS —e.g. fear of being abandoned, left alone, being with others d. REPETITIVE HEALTH COMPLAINTS —e.g. persistently seeks medical attention, obsessive concern with body functions e. REPETITIVE ANXIOUS COMPLAINTS, CONCERNS —e.g. persistently seeks attention/ reassurance regarding schedules, meals, laundry, clothing, relationship issues f. SAD, PAINED, WORRIED FACIAL EXPRESSIONS —e.g. furrowed brows g. RECURRENT CRYING, TEARFULNESS h. WITHDRAWAL FROM ACTIVITIES OF INTEREST —e.g. no interest in long standing activities or being with family/friends i. REDUCED SOCIAL INTERACTION	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
2	MOOD DECLINE	Mood indicators have become worse as compared to status of 90 days ago (or since last assessment if less than 90 days) 0. No 1. Yes	<input type="checkbox"/>
3	BEHAVIOURAL SYMPTOMS	Instances when client exhibited behavioural symptoms. If EXHIBITED, ease of altering the symptom when it occurred. 0. Did not occur in last 3 days 1. Occurred, easily altered 2. Occurred, not easily altered a. WANDERING —Moved with no rational purpose, seemingly oblivious to needs or safety b. VERBALLY ABUSIVE BEHAVIOURAL SYMPTOMS —Threatened, screamed at, cursed at others c. PHYSICALLY ABUSIVE BEHAVIOURAL SYMPTOMS —Hit, shoved, scratched, sexually abused others d. SOCIALLY INAPPROPRIATE/ DISRUPTIVE BEHAVIOURAL SYMPTOMS —Disruptive sounds, noisiness, screaming, self-abusive acts, sexual behaviour or disrobing in public, smears/ throws food/faeces, rummaging, repetitive behaviour, rises early and causes disruption e. RESISTS CARE —Resisted taking medications/ injections, ADL assistance, eating, or changes in position	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
4	CHANGES IN BEHAVIOUR SYMPTOMS	Behavioural symptoms have become worse or are less well tolerated by family as compared to 90 DAYS AGO (or since last assessment if less than 90 days) 0. No, or no change in behavioural symptoms or acceptance by family 1. Yes	<input type="checkbox"/>

SECTION F. SOCIAL FUNCTIONING			
1	INVOLVE-MENT	a. At ease interacting with others (e.g. likes to spend time with others) 0. At ease 1. Not at ease b. Openly expresses conflict or anger with family/friends 0. No 1. Yes	<input type="checkbox"/> <input type="checkbox"/>
2	CHANGE IN SOCIAL ACTIVITIES	As compared to 90 DAYS AGO (or since last assessment if less than 90 days ago), decline in the client's level of participation in social, religious, occupational or other preferred activities. IF THERE WAS A DECLINE, client distressed by this fact 0. No decline 1. Decline, not distressed 2. Decline, distressed	<input type="checkbox"/>
3	ISOLATION	a. Length of time client is alone during the day (morning and afternoon) 0. Never or hardly ever 1. About one hour 2. Long periods of time—e.g. all morning 3. All of the time b. Client says or indicates that he/she feels lonely 0. No 1. Yes	<input type="checkbox"/> <input type="checkbox"/>

SECTION G. INFORMAL SUPPORT SERVICES												
1	TWO KEY INFORMAL HELPERS Primary (A) and Secondary (B)	NAME OF PRIMARY AND SECONDARY HELPERS a. (Last/Family Name) b. (First Name) c. (Last/Family Name) d. (First Name) <table border="1"> <thead> <tr> <th></th> <th>(A) Pri</th> <th>(B) Sec</th> </tr> </thead> <tbody> <tr> <td>e. Lives with client 0. Yes 1. No 2. No such helper (skip other items in the appropriate column)</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> <tr> <td>f. Relationship to client 0. Child or child-in-law 1. Spouse 2. Other relative or whanau 3. Friend/neighbour</td> <td><input type="checkbox"/></td> <td><input type="checkbox"/></td> </tr> </tbody> </table>			(A) Pri	(B) Sec	e. Lives with client 0. Yes 1. No 2. No such helper (skip other items in the appropriate column)	<input type="checkbox"/>	<input type="checkbox"/>	f. Relationship to client 0. Child or child-in-law 1. Spouse 2. Other relative or whanau 3. Friend/neighbour	<input type="checkbox"/>	<input type="checkbox"/>
	(A) Pri	(B) Sec										
e. Lives with client 0. Yes 1. No 2. No such helper (skip other items in the appropriate column)	<input type="checkbox"/>	<input type="checkbox"/>										
f. Relationship to client 0. Child or child-in-law 1. Spouse 2. Other relative or whanau 3. Friend/neighbour	<input type="checkbox"/>	<input type="checkbox"/>										
		Areas of help: 0. Yes 1. No g. Advice or emotional support h. IADL care i. ADL care If needed, willingness (with ability) to increase help: 0. More than 2 hours per day 1. 1–2 hours per day 2. No j. Emotional support k. IADL care l. ADL care										
2	CAREGIVER STATUS	(Check all that apply) A caregiver is unable to continue in caring activities—e.g. decline in the health of the caregiver makes it difficult to continue Primary caregiver is not satisfied with support received from family and friends (e.g. other children of client) Primary caregiver expresses feelings of distress, anger or depression NONE OF ABOVE										

Name of Client _____

NHI Number _____

3	EXTENT OF INFORMAL HELP (HOURS OF CARE, ROUNDED)	For instrumental and personal activities of daily living received over the LAST 7 DAYS , indicate extent of help from family, friends, and neighbours	HOURS	
		a. Sum of time across five weekdays	<input type="text"/>	<input type="text"/>
		b. Sum of time across two weekend days	<input type="text"/>	<input type="text"/>

SECTION H. PHYSICAL FUNCTIONING:
 • IADL PERFORMANCE IN 7 DAYS
 • ADL PERFORMANCE IN 3 DAYS

1	IADL SELF-PERFORMANCE —Code for functioning in routine activities around the home or in the community during the LAST 7 DAYS .			
	(A) IADL SELF-PERFORMANCE CODE (Code for client's performance during LAST 7 DAYS)			
	0. INDEPENDENT —did on own			
	1. SOME HELP —help some of the time			
	2. FULL HELP —performed with help all of the time			
	3. BY OTHERS —performed by others			
	8. ACTIVITY DID NOT OCCUR			
	(B) IADL DIFFICULTY CODE How difficult it is (or would it be) for client to do activity on own			
	0. NO DIFFICULTY			
	1. SOME DIFFICULTY —e.g. needs some help, is very slow, or fatigues			
2. GREAT DIFFICULTY —e.g. little or no involvement in the activity is possible				
a. MEAL PREPARATION —How meals are prepared (e.g. planning meals, cooking, assembling ingredients, setting out food and utensils)			<input type="text"/>	<input type="text"/>
b. ORDINARY HOUSEWORK —How ordinary work around the house is performed (e.g. doing dishes, dusting, making bed, tidying up, laundry)			<input type="text"/>	<input type="text"/>
c. MANAGING FINANCES —How bills are paid, cheque book is balanced, household expenses are balanced			<input type="text"/>	<input type="text"/>
d. MANAGING MEDICATIONS —How medications are managed (e.g. remembering to take medicines, opening bottles, taking correct drug dosages, giving injections, applying ointments)			<input type="text"/>	<input type="text"/>
e. PHONE USE —How telephone calls are made or received (with assistive devices such as large numbers on telephone, amplification as needed)			<input type="text"/>	<input type="text"/>
f. SHOPPING —How shopping is performed for food and household items (e.g. selecting items, managing money)			<input type="text"/>	<input type="text"/>
g. TRANSPORTATION —How client travels by vehicle (e.g. gets to places beyond walking distance)			<input type="text"/>	<input type="text"/>

2	ADL SELF-PERFORMANCE —The following address the client's physical functioning in routine personal activities of daily life, for example, dressing, eating, etc. during the LAST 3 DAYS , considering all episodes of these activities. For clients who performed an activity independently, be sure to determine and record whether others encouraged the activity or were present to supervise or oversee the activity (Note—For bathing, code for most dependent single episode in LAST 7 DAYS.)	
	0. INDEPENDENT —No help, setup, or oversight—OR—Help, setup, oversight provided only 1 or 2 times (with any task or subtask)	
	1. SETUP HELP ONLY —Article or device provided within reach of client 3 or more times	
	2. SUPERVISION —Oversight, encouragement or cueing provided 3 or more times during last 3 days—OR—Supervision (1 or more times) plus physical assistance provided only 1 or 2 times (for a total of 3 or more episodes of help or supervision)	
	3. LIMITED ASSISTANCE —Client highly involved in activity; received physical help in guided manoeuvring of limbs or other non-weight bearing assistance 3 or more times —OR— Combination of non-weight bearing help with more help provided only 1 or 2 times during period (for a total of 3 or more episodes of physical help)	
	4. EXTENSIVE ASSISTANCE —Client performed part of activity on own (50% or more of subtasks), but help of following type(s) were provided 3 or more times: — Weight-bearing support—OR— — Full performance by another during part (but not all) of last 3 days	
	5. MAXIMAL ASSISTANCE —Client involved and completed less than 50% of subtasks on own (includes 2+ person assist), received weight bearing help or full performance of certain subtasks 3 or more times	
	6. TOTAL DEPENDENCE —Full performance of activity by another	
	8. ACTIVITY DID NOT OCCUR (regardless of ability)	
	a. MOBILITY IN BED —Including moving to and from lying position, turning side to side, and positioning body while in bed.	
b. TRANSFER —Including moving to and between surfaces—to/from bed, chair, wheelchair, standing position. (Note—Excludes to/from bath/toilet)		<input type="text"/>
c. MOBILITY IN HOME —(Note—If in wheelchair, self-sufficiency once in chair.)		<input type="text"/>
d. MOBILITY OUTSIDE OF HOME —(Note—If in wheelchair, self-sufficiency once in chair.)		<input type="text"/>
e. DRESSING UPPER BODY —How client dresses and undresses (street clothes, underwear) above the waist, includes prostheses, orthotics, fasteners, pullovers, etc.		<input type="text"/>
f. DRESSING LOWER BODY —How client dresses and undresses (street clothes, underwear) from the waist down, includes prostheses, orthotics, belts, pants, skirts, shoes, and fasteners.		<input type="text"/>
g. EATING —Including taking in food by any method, including tube feedings.		<input type="text"/>
h. TOILET USE —Including using the toilet room or commode, bedpan, urinal, transferring on/off toilet, cleaning self after toilet use or incontinent episode, changing pad, managing any special devices required (ostomy or catheter), and adjusting clothes.		<input type="text"/>
i. PERSONAL HYGIENE —Including combing hair, brushing teeth, shaving, applying makeup, washing/drying face and hands (EXCLUDE baths and showers).		<input type="text"/>
j. BATHING —How client takes full-body bath/shower or sponge bath (EXCLUDE washing of back and hair). Includes how each part of body is bathed: arms, upper and lower legs, chest abdomen, perineal area. Code for most dependent episode in LAST 7 DAYS.		<input type="text"/>
3	ADL DECLINE —ADL status has become worse (i.e. now more impaired in self-performance) as compared to status 90 days ago (or since last assessment if less than 90 days)	<input type="text"/>
		0. No 1. Yes

Name of Client _____

NHI Number _____

4	PRIMARY MODES OF MOBILITY	0. No assistive device 1. Stick 2. Walker/crutch 3. Mobility Scooter a. Indoors <input type="checkbox"/> b. Outdoors <input type="checkbox"/>	4. Wheelchair 8. ACTIVITY DID NOT OCCUR
5	STAIR CLIMBING	In the last 3 days , how client went up and down stairs (e.g. single or multiple steps, using handrail as needed). 0. Up and down stairs without help 1. Up and down stairs with help 2. Not go up and down stairs	<input type="checkbox"/>
6	STAMINA	a. In a typical week, during the LAST 30 DAYS (or since last assessment), code the number of days client usually went out of the house or building in which client lives (no matter how short a time period) 0. Every day 1. 2-6 days a week 2. 1 day a week 3. No days b. Hours of physical activities in the last 3 days (e.g. walking, cleaning house, exercise) 0. Two or more hours 1. Less than two hours	<input type="checkbox"/> <input type="checkbox"/>
7	FUNCTIONAL POTENTIAL	(Check all that apply) Client believes he/she capable of increased functional independence (ADL, IADL, mobility) <input type="checkbox"/> a. Caregivers believe client is capable of increased functional independence (ADL, IADL, mobility) <input type="checkbox"/> b. Good prospects of recovery from current disease or conditions, improved health status expected <input type="checkbox"/> c. NONE OF ABOVE <input type="checkbox"/> d.	

SECTION I. CONTINENCE IN LAST 7 DAYS									
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3	BOWEL CONTINENCE	In LAST 7 DAYS (or since last assessment if less than 7 days), control of bowel movement (with appliance or bowel continence programme if employed) 0. CONTINENT —Complete control; DOES NOT USE ostomy device 1. CONTINENT WITH OSTOMY —Complete control with use of ostomy device that does not leak stool 2. USUALLY CONTINENT —Bowel incontinent episodes less than weekly 3. OCCASIONALLY INCONTINENT —Bowel incontinent episodes once a week 4. FREQUENTLY INCONTINENT —Bowel incontinent episodes 2–3 times a week 5. INCONTINENT —Bowel incontinent all (or almost all) of the time 8. DID NOT OCCUR —No bowel movement during entire 7 day assessment period	<input type="checkbox"/>
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2	OTHER CURRENT OR MORE DETAILED DIAGNOSES AND ICD-10- CA CODES	a.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
		b.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
		c.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
		d.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

SECTION K. HEALTH CONDITIONS AND PREVENTIVE HEALTH MEASURES

1	PREVENTIVE HEALTH (PAST TWO YEARS)	(Check all that apply—in PAST 2 YEARS)									
		Blood pressure measured	a.	IF FEMALE: Received breast examination or mammography	d.						
		Received influenza vaccination	b.	NONE OF ABOVE	e.						
		Test for blood in stool or screening endoscopy	c.								
2	PROBLEM CONDITIONS PRESENT ON 2 OR MORE DAYS	(Check all that were present on at least 2 of the last 3 days)									
		Diarrhoea	a.	Loss of appetite	d.						
		Difficulty urinating or urinating 3 or more times at night	b.	Vomiting	e.						
		Fever	c.	NONE OF ABOVE	f.						
3	PROBLEM CONDITIONS	(Check all present at any point during last 3 days)									
		PHYSICAL HEALTH				MENTAL HEALTH					
		Chest pain/pressure at rest or on exertion	a.	Delusions	f.						
		No bowel movement in 3 days	b.	Hallucinations	g.						
		Dizziness or lightheadedness	c.	NONE OF ABOVE	h.						
		Oedema	d.								
		Shortness of breath	e.								
		4	PAIN	a. Frequency with which client complains or shows evidence of pain 0. No pain (score b–e as 0) 1. Less than daily 2. Daily—one period 3. Daily—multiple periods (e.g. morning and evening)							
				b. Intensity of pain 0. No pain 1. Mild 2. Moderate 3. Severe 4. Times when pain is horrible or excruciating							
				c. From client's point of view, pain intensity disrupts usual activities 0. No 1. Yes							
d. Character of pain 0. No pain 1. Localized—single site 2. Multiple sites											
5	FALLS FREQUENCY	e. From client's point of view, medications adequately control pain 0. Yes or no pain 1. Medications do not adequately control pain 2. Pain present, medication not taken									
		Number of times fell in LAST 90 DAYS (or since last assessment if less than 90 days). If none, code "0"; if more than 9, code "9".									

6	DANGER OF FALL	(Code for danger of falling) 0. No 1. Yes			
		a. Unsteady gait	<input type="text"/>		
		b. Client limits going outdoors due to fear of falling (e.g. stopped using bus, goes out only with others)			
7	LIFESTYLE (Drinking/ Smoking)	(Code for drinking or smoking) 0. No 1. Yes			
		a. In the LAST 90 DAYS (or since last assessment if less than 90 days), client felt the need or was told by others to cut down on drinking, or others were concerned with client's drinking			
		b. In the LAST 90 DAYS (or since last assessment if less than 90 days), client had to have a drink first thing in the morning to steady nerves (i.e. an "eye opener") or has been in trouble because of drinking			
		c. Smoked or chewed tobacco daily			
8	HEALTH STATUS INDICATORS	(Check all that apply)			
		Client feels he/she is poor health (when asked)	a.	Treatments changed in LAST 30 DAYS (or since last assessment if less than 30 days) because of a new acute episode or condition	d.
		Has conditions or diseases that make cognition, ADL, mood, or behaviour patterns unstable (fluctuations, precarious, or deteriorating)	b.	Prognosis of less than six months to live—e.g. Physician/GP has told client or client's family that client has end-stage disease	e.
		Experiencing a flare-up of a recurrent or chronic problem	c.	NONE OF ABOVE	f.
		9	OTHER STATUS INDICATORS	(Check all that apply)	
				Fearful of a family member or caregiver	a.
		Unusually poor hygiene	b.	NONE OF ABOVE	f.
		Unexplained injuries, broken bones, or burns	c.		
		Neglected, abused, or mistreated	d.		

SECTION L. NUTRITION/HYDRATION STATUS

1	WEIGHT	(Code for weight items) 0. No 1. Yes	
		a. Unintended weight loss of 5% or more in the LAST 30 DAYS (or 10% or more in the LAST 180 DAYS)	
		b. Severe malnutrition (cachexia)	
		c. Morbid obesity	
2	CONSUMPTION	(Code for consumption) 0. No 1. Yes	
		a. In at least 2 of the last 3 days, ate one or fewer meals a day	
		b. In last 3 days, noticeable decrease in the amount of food client usually eats or fluids usually consumes	
		c. Insufficient fluid—did not consume all/almost all fluids during last 3 days	
		d. Enteral tube feeding	

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3	SWALLOWING	0. NORMAL —Safe and efficient swallowing of all diet consistencies 1. REQUIRES DIET MODIFICATION TO SWALLOW SOLID FOODS (mechanical diet or able to ingest specific foods only) 2. REQUIRES MODIFICATION TO SWALLOW SOLID FOODS AND LIQUIDS (puree, thickened liquids) 3. COMBINED ORAL AND TUBE FEEDING 4. NO ORAL INTAKE (NPO)	<input type="checkbox"/>
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SECTION M. DENTAL STATUS (ORAL HEALTH)			
1	ORAL STATUS	(Check all that apply) Problem chewing (e.g. poor mastication, immobile jaw, surgical resection, decreased sensation/motor control, pain while eating) Mouth is "dry" when eating a meal Problem brushing teeth or dentures NONE OF ABOVE	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

SECTION N. SKIN CONDITION			
1	SKIN PROBLEMS	Any trouble skin conditions or changes in skin condition (e.g. burns, bruises, rashes, itchiness, body lice, scabies)	<input type="checkbox"/>
		0. No 1. Yes	
2	ULCERS (Pressure/Stasis)	Presence of an ulcer anywhere on the body. Ulcers include any area of persistent skin redness (Stage 1); partial loss of skin layers (Stage 2); deep craters in the skin (Stage 3); breaks in skin exposing muscle or bone (Stage 4). [Code 0 if no ulcer, otherwise record the highest ulcer stage (Stage 1–4).] a. Pressure ulcer —any lesion caused by pressure, shear forces, resulting in damage of underlying tissues b. Stasis ulcer —open lesion caused by poor circulation in the lower extremities	<input type="checkbox"/> <input type="checkbox"/>
3	OTHER SKIN PROBLEMS REQUIRING TREATMENT	(Check all that apply) Burns (second or third degree) Open lesions other than ulcers, rashes, cuts (e.g. cancer) Skin tears or cuts Surgical wound Corns, calluses, structural problems, infections, fungi NONE OF ABOVE	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
4	HISTORY OF RESOLVED PRESSURE ULCERS	Client previously had (at any time) or has an ulcer anywhere on the body.	<input type="checkbox"/>
		0. No 1. Yes	
5	WOUND/ULCER CARE	(Check for formal care in LAST 7 DAYS) Antibiotics, systemic or topical Dressings Surgical wound care Other wound/ulcer care (e.g. pressure relieving device, nutrition, turning, debridement) NONE OF ABOVE	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

SECTION O. ENVIRONMENTAL ASSESSMENT			
1	HOME ENVIRONMENT	(Check any of following that make home environment hazardous or uninhabitable (if none apply, check NONE OF ABOVE, if temporarily in institution, base assessment on home visit)) Lighting in evening (including inadequate or no lighting in living room, sleeping room, kitchen, toilet, corridors) Flooring and carpeting (e.g. holes in floor, electric wires where client walks, mats/rugs) Bathroom and toilet room (e.g. non-operating toilet, leaking pipes, no rails though needed, slippery bathtub, outside toilet) Kitchen (e.g. dangerous stove, inoperative refrigerator, infestation by rats or bugs) Heating and cooling (e.g. too hot in summer, too cold in winter, wood burner/stove in a home with an asthmatic) Personal safety (e.g. fear of violence, safety problem in going to mail/letter box or visiting neighbours, heavy traffic in street) Access to home (e.g. difficulty entering/leaving home) Access to rooms in house (e.g. unable to climb stairs) NONE OF ABOVE	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
2	LIVING ARRANGEMENT	a. As compared to 90 DAYS AGO (or since last assessment), client now lives with other persons—e.g. moved in with another person, other moved in with client 0. No 1. Yes b. Client or primary caregiver feels that client would be better off in another living environment 0. No 1. Client only 2. Caregiver only 3. Client and caregiver	<input type="checkbox"/> <input type="checkbox"/>

SECTION P. SERVICE UTILIZATION (IN LAST 7 DAYS)																																																										
1	FORMAL CARE (Minutes rounded to even 10 minutes)	Extent of care or care management in LAST 7 DAYS (or since last assessment if less than 7 days) since involving <table border="1"> <thead> <tr> <th></th> <th># of</th> <th>(A) Days</th> <th>(B) Hours</th> <th>(C) Mins</th> </tr> </thead> <tbody> <tr> <td>a. Personal care/support services</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>b. Visiting nurses</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>c. Household management services</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>d. Meals</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>e. Volunteer services</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>f. Physiotherapy</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>g. Occupational therapy</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>h. Speech & Lang therapy</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>i. Day care or day hospital</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>j. Social worker</td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table>		# of	(A) Days	(B) Hours	(C) Mins	a. Personal care/support services					b. Visiting nurses					c. Household management services					d. Meals					e. Volunteer services					f. Physiotherapy					g. Occupational therapy					h. Speech & Lang therapy					i. Day care or day hospital					j. Social worker					
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Name of Client _____

NHI Number _____

2	SPECIAL TREATMENTS, THERAPIES, PROGRAMMES	<p>Special treatments, therapies, and programmes received or scheduled during the LAST 7 DAYS (or since last assessment if less than 7 days) and adherence to the required schedule. Includes services received in the home or on an outpatient basis. (Blank) Not applicable</p> <p>1. Scheduled, full adherence as prescribed 2. Scheduled, partial adherence 3. Scheduled, not received (If no treatments provided, check NONE OF ABOVE P2aa)</p> <table border="1"> <thead> <tr> <th data-bbox="412 474 602 506">RESPIRATORY TREATMENTS</th> <th data-bbox="607 474 781 506">THERAPIES</th> </tr> </thead> <tbody> <tr> <td data-bbox="412 512 570 543">a. Oxygen</td> <td data-bbox="607 512 781 543">n. Exercise therapy</td> </tr> <tr> <td data-bbox="412 550 570 602">b. Respirator for assistive breathing</td> <td data-bbox="607 550 781 602">o. Occupational therapy</td> </tr> <tr> <td data-bbox="412 609 570 661">c. All other respiratory treatments</td> <td data-bbox="607 609 781 661">p. Physiotherapy</td> </tr> <tr> <th data-bbox="412 667 602 699">OTHER TREATMENTS</th> <th data-bbox="607 667 781 699">PROGRAMMES</th> </tr> <tr> <td data-bbox="412 705 570 737">d. Alcohol/drug treatment programme</td> <td data-bbox="607 705 781 737">q. Day centre</td> </tr> <tr> <td data-bbox="412 743 570 774">e. Blood transfusion(s)</td> <td data-bbox="607 743 781 774">r. Day hospital</td> </tr> <tr> <td data-bbox="412 781 570 812">f. Chemotherapy</td> <td data-bbox="607 781 781 812">s. Hospice care</td> </tr> <tr> <td data-bbox="412 819 570 850">g. Dialysis</td> <td data-bbox="607 819 781 850">t. Physician/GP or clinic visit</td> </tr> <tr> <td data-bbox="412 856 570 888">h. IV infusion—central</td> <td data-bbox="607 856 781 888">u. Respite care</td> </tr> <tr> <td data-bbox="412 894 570 947">i. IV infusion—peripheral</td> <th data-bbox="607 894 781 947">SPECIAL PROCEDURES DONE IN HOME</th> </tr> <tr> <td data-bbox="412 953 570 1005">j. Medication by injection</td> <td data-bbox="607 953 781 1005">v. Daily nurse monitoring (e.g. ECG, urinary output)</td> </tr> <tr> <td data-bbox="412 1012 570 1043">k. Ostomy care</td> <td data-bbox="607 1012 781 1043">w. Nurse monitoring less than daily</td> </tr> <tr> <td data-bbox="412 1050 570 1102">l. Radiation</td> <td data-bbox="607 1050 781 1102">x. Medical alert bracelet or electronic security alert</td> </tr> <tr> <td data-bbox="412 1108 570 1161">m. Tracheostomy care</td> <td data-bbox="607 1108 781 1161">y. Skin treatment</td> </tr> <tr> <td></td> <td data-bbox="607 1167 781 1199">z. Special diet</td> </tr> <tr> <td></td> <td data-bbox="607 1205 781 1236">aa. NONE OF ABOVE</td> </tr> </tbody> </table>	RESPIRATORY TREATMENTS	THERAPIES	a. Oxygen	n. Exercise therapy	b. Respirator for assistive breathing	o. Occupational therapy	c. All other respiratory treatments	p. Physiotherapy	OTHER TREATMENTS	PROGRAMMES	d. Alcohol/drug treatment programme	q. Day centre	e. Blood transfusion(s)	r. Day hospital	f. Chemotherapy	s. Hospice care	g. Dialysis	t. Physician/GP or clinic visit	h. IV infusion—central	u. Respite care	i. IV infusion—peripheral	SPECIAL PROCEDURES DONE IN HOME	j. Medication by injection	v. Daily nurse monitoring (e.g. ECG, urinary output)	k. Ostomy care	w. Nurse monitoring less than daily	l. Radiation	x. Medical alert bracelet or electronic security alert	m. Tracheostomy care	y. Skin treatment		z. Special diet		aa. NONE OF ABOVE	5	TREATMENT GOALS	Any treatment goals that have been met in the LAST 90 DAYS (or since last assessment if less than 90 days)? 0. No 1. Yes	<input type="checkbox"/>
RESPIRATORY TREATMENTS	THERAPIES																																							
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6	OVERALL CHANGE IN CARE NEEDS	Overall self-sufficiency has changed significantly as compared to status of 90 DAYS AGO (or since last assessment if less than 90 days) 0. No change 1. Improved—receives fewer supports 2. Deteriorated—receives more support	<input type="checkbox"/>																																					
7	TRADE OFFS	Because of limited funds, during the last month, client made trade-offs among purchasing any of the following: prescribed medications, sufficient home heat, necessary Physician/GP care, adequate food, home care 0. No 1. Yes	<input type="checkbox"/>																																					
SECTION Q. MEDICATIONS																																								
1	NUMBER OF MEDICATIONS	Record the number of different medicines (prescriptions and over the counter), including eye drops, taken regularly or on an occasional basis in the LAST 7 DAYS (or since last assessment) [If none, code "0", if more than 9, code "9".]	<input type="checkbox"/>																																					
2	RECEIPT OF PSYCHOTROPIC MEDICATION	Psychotropic medications taken in the LAST 7 DAYS (or since last assessment) [Note—Review client's medications with the list that applies to the following categories.] 0. No 1. Yes a. Antipsychotic/neuroleptic b. Anxiolytic c. Antidepressant d. Hypnotic	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>																																					
3	MEDICAL OVERSIGHT	Physician/GP reviewed client's medications as a whole in LAST 180 DAYS (or since last assessment) 0. Discussed with at least one Physician/GP (or no medication taken) 1. No single Physician/GP reviewed all medications	<input type="checkbox"/>																																					
4	COMPLIANCE/ADHERENCE WITH MEDICATIONS	Compliant all or most of time with medications prescribed by Physician/GP (both during and between therapy visits) in LAST 7 DAYS 0. Always compliant 1. Compliant 80% of time or more 2. Compliant less than 80% of time, including failure to purchase prescribed medications 3. NO MEDICATIONS PRESCRIBED	<input type="checkbox"/>																																					
3	MANAGEMENT OF EQUIPMENT (In Last 3 Days)	<p>Management codes: 0. Not used 1. Managed on own 2. Managed on own if laid out or with verbal reminders 3. Partially performed by others 4. Fully performed by others</p> <p>a. Oxygen <input type="checkbox"/></p> <p>b. IV <input type="checkbox"/></p> <p>c. Catheter <input type="checkbox"/></p> <p>d. Ostomy <input type="checkbox"/></p>																																						
4	VISITS IN LAST 90 DAYS OR SINCE LAST ASSESSMENT	<p>Enter "0" if none, if more than 9, code "9"</p> <p>a. Number of times ADMITTED TO HOSPITAL with an overnight stay <input type="checkbox"/></p> <p>b. Number of times VISITED EMERGENCY ROOM without an overnight stay <input type="checkbox"/></p> <p>c. EMERGENT CARE—including unscheduled nursing, Physician/GP, or therapeutic visits to office or home <input type="checkbox"/></p>																																						

Name of Client _____ NHI Number _____

Q5 LIST OF ALL MEDICATIONS				
List prescribed and nonprescribed medications taken in LAST 7 DAYS (or since last assessment)				
a. Medication Name and Dose: name (generic or trade names are both acceptable) of the medication, as well as the dose ordered				
b. Number Taken: the amount of medication administered each time the medication is given. Number taken is not always the dose. Rather, it is the number of tablets, capsules, suppositories, or amount of liquid (cc's, mls, units) per dose that is administered to the resident				
c. Form: Code the route of Administration using the following list:				
1. By mouth (PO) 2. Sub lingual (SL) 3. Intramuscular (IM) 4. Intravenous (IV) 5. Subcutaneous (SQ) 6. Rectal (R) 7. Topical 8. Inhalation 9. Enteral tube 10. Other				
d. Frequency: Code the number of times per day, week, or month the medication is administered using the following list:				
PRN As necessary QH Every hour Q2H Every two hours Q3 H Every three hours Q4 H Every four hours Q6 H Every six hours Q8H Every eight hours QD Once daily HS Bedtime BID Two times daily (includes every 12 hours) TID Three times daily QID Four times daily 5D Five times daily QOD Every other day QW Once each week 2W Two times every week 3W Three times every week 4W Four times every week 5W Five times every week 6W Six times every week 1M Once every month 2M Twice every month C Continuous O Other				
e. If PRN: record number of doses taken in last 7 days.				
a. Medication Name and Dose	b. Number Taken	c. Form	d. Frequency	e. If PRN: # doses
a				
b				
c				
d				
e				
f				
g				
h				
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w				
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z				
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cc				
dd				

Name of Client _____

NHI Number _____

SECTION R. ASSESSMENT INFORMATION			
1	SIGNATURES OF PERSONS COMPLETING THE ASSESSMENT		
	a. Signature of Assessment Coordinator		
	b. Title of Assessment Coordinator		
	c. Date Assessment Coordinator signed as complete		
	<div style="display: inline-block; border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="display: inline-block; border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="display: inline-block; border: 1px solid black; width: 20px; height: 20px; margin-right: 5px;"></div> <div style="display: inline-block; border: 1px solid black; width: 20px; height: 20px;"></div>		
	Day	Month	Year
	Other Signatures	Title	Sections

REFERENCES

- Age Concern New Zealand. (2007). Submission to Commerce Committee. Retrieved 6 December 2009, from <http://www.ageconcern.org.nz/files/file/Submission-housinginquiry-15Jun07.pdf>.
- Ageinplace.com. (2008A). Your aging in place plan. Retrieved 24 January 2010, from <http://ageinplace.com/what-is-aging-in-place/your-aging-in-place-plan/>.
- Ageinplace.com. (2008B). The Five Key Risks All Retirees Face. Retrieved 24 January 2010, from <http://ageinplace.com/the-five-key-risks-all-retirees-face/>.
- Alecxih, L., Lutsky, S., Corea, J., & Coleman, B. (1996). Estimated cost savings from the use of home and community based alternatives to nursing facility care in three states. Working Paper 9618, American Association of Retired Persons, Washington, DC.
- Alpass, F., and Mortimer, Ruth. (2007). Ageing Workforces and Ageing Occupations: A Discussion Paper. Massey University. Retrieved 16 January 2010, from <http://www.search.dol.govt.nz/index.html?q=age+future+workforce&qwithin%5B%5D=All+sites&SearchSubmit=Search>.
- Altman, D., and Bland, J. (1995). Absence of evidence is not evidence of absence. Retrieved 17 March 2010, from <http://www.bmj.com/cgi/content/full/311/7003/485>.
- Anderson, G., & Hussey, P. (2000). Population Aging: A Comparison Among Industrialized Countries. Health Affairs May/June: 191-203.
- Asakawa, K., & Feeny, D. (2006) Construct Validity of the Health Utilities Index Mark 3 (HUI3): Alzheimer Disease, Arthritis and Cataract. Presented at Economics of Population Health: Inaugural Conference of the American Society of Health Economists. January 2006.

Baxendine, L. (2009). There's more to the future than just dollars. Retrieved 3 March 2010, from <http://www.ageconcern.org.nz/whatwearesaying/theres-more-future-just-dollars>.

Beehive.govt.nz. (2009B). Bill English New Zealand Superfund Fact Sheet. Retrieved 3 March 2010, from <http://www.beehive.govt.nz/release/new+zealand+super+fund+-+fact+sheet>.

Beehive.govt.nz. (2009A). John Key Speech to Gray Power Annual Meeting. Retrieved 3 March 2010, from <http://www.beehive.govt.nz/speech/speech+grey+power+annual+meeting+marton> .

Bernheim, J., Verbinnen, R., De Boever, S., Teerltynck, W., & Mets, T. (1995). Evaluation, not description, of quality of life by global self-assessment. *Quality of Life Research*, 4 (5). 398.

Briscoe, Tracey. (2004). DHBs face funding predicament. Retrieved 13 November 2009, from <http://www.nzma.org.nz/news/issues/editorial.html>.

Carr, A., & Higginson, I. (2001). Measuring Quality of Life: Are Quality of Life Measures Patient Centred? *British Medical Journal*, 322(7298): 1357-1360.

CDC. (2009). Healthy Places Terminology. Retrieved 24 January 2010, from <http://www.cdc.gov/healthyplaces/terminology.htm>

CDHB. (2005). Support Needs Level (Ref 1334). Ministry of Health, Support Care Development Group.

Cox, D. (1982). Statistical Significance Tests. *British Journal of Clinical Pharmacology*, 14, 325-331.

Dallal, G. (2008A). Why $P=0.05$. Retrieved 17 March 2010, from <http://www.jerrydallal.com/LHSP/p05.htm>.

Dallal, G. (2008B). P Values. Retrieved 17 March 2010, from <http://www.jerrydallal.com/LHSP/pval.htm>

Dalziel, L. (2001). Minister for Senior Citizens. Retrieved 18 November 2009 from <http://www.osc.govt.nz/positive-ageing-strategy/publication/ministers-foreward.html>.

Davey, Judith. (2006). Ageing in Place: The views of older homeowners on maintainance, renovation and adaptation. *Social Policy Journal of New Zealand*. 27(March): 128-141.

Diener, E, & Suh, E. (1997). Measuring Quality of Life: Economic, Social, and Subjective Indicators. *Social Indicators Research*, 40: 189-216.

Dunston, K. & Thomson, N. (March 2006). Demographic Aspects of New Zealand's Ageing Population. Retrieved 24 October 2009 from <http://www.stats.govt.nz/reports/papers/demographic-aspects-nz-ageing-population.aspx>

Fayers, P., Hand, D., Bjordal, K., & Groenvold, M. (1997). Causal Indicators in Quality of Life Research. *Quality of Life Research*, 6, 393-406.

Feeny,D., Furlong, W., Boyle, M., and Torrance, G. (1995). Multi-Attribute Health Status Classification Systems: Health Utility Index. *PharmacoEconomics*, 7 (6), 490 – 502.

Felce, D., & Perry, J. (1995). Quality of Life: its Definition and Measurement. *Research in Developmental Disabilities*, 16(1): 51.

Fries BE, Schneider DP., Foley JW., Gavazzi M., Burke R., Cornelius E. (1994). Refining a case-mix measure for nursing homes: Resource Utilization Groups (RUG-III). *Medical Care* 32(7): 668-685.

Fries BE, & Fahey CJ. (2003). Introduction: Lessons Learned from Eight Cases. Implementing the Resident Assessment Instrument: Case Studies of Policymaking for Long-Term Care in Eight Countries. Milbank Memorial Fund.

Gilhooley, K. (2008). Implementing the InterRAI - A DHB Experience [Powerpoint]. Canterbury District Health Board, New Zealand.

Gordon, Mary. (2009). Minutes of the Canterbury District Health Board Meeting Held in the Board Room, Te Waipounamu House on Friday 13 February 2009 commencing at 9.00am. Retrieved 1 March 2010, from <http://www.cdhb.govt.nz/CorpBrd/HACMeetings/2009/03@Apr02/MINS%20-%20Board%20Public%20-%2013%20February%202009.pdf>

Gordon, Mary. (2010). Personal Communication, 1 March 2010.

Grabowski, D. (2006). The Cost-Effectiveness of Noninstitutional Long-Term Care Services : Review and Synthesis of the Most Recent Evidence. *Medical Care Research and Review*, 63(1), 4.

Gregory, D., Johnston, R., Pratt, G., Watts, M., & Whatmore, S. (2009). *The Dictionary of Human Geography*.

Gruber, J. & Wise D. (2002). Social Security Programs and Retirement Around the World: Micro Estimation. National Bureau of Economic Research, Working Paper 9407.

Hambleton, P., Keeling, S., & McKenzie, M. (2009). The jungle of quality of life: mapping measures and meanings for elders. *Australasian Journal on Ageing*, 28 (1), 3-6.

Hawes, C., Morris, J., Phillips, C., Mor, V., Fries, B., & Nonemaker, S. (1995). Reliability Estimates for the Minimum Data Set for Nursing Home Resident Assessment and Care Screening (MDS). *The Gerontologist*. 35 (2), 172-178.

Health Utilities. (2010). Welcome to Health Utilities, Inc. Retrieved 12 January 2010, from <http://www.healthutilities.com/>.

Horsman, J., Furlong, W., Feeny, D., & Torrance, G. (2003). The Health Utilities Index (HUI): concepts, measurement properties and applications. *Health and Quality of Life Outcomes* 1(54). Retrieved 12 January 2010 from <http://www.healthutilities.com/>.

Hughes, S., Cummings, J., Weaver, F., Manheim, L., Braun, B., Conrad, K. (1991). A Randomized Trial of the Cost Effectiveness of VA Hospital-Based Home Care for the Terminally Ill. *Health Services Research*. 801-817.

Hurnard, Roger. (2005A). The effect of New Zealand Superannuation eligibility age on the labour force participation of older people. New Zealand Treasury, Working Paper 2005/2009.

Hurnard, Roger. (2005B). The Effect of NZ Superannuation eligibility age on the labour force participation of older people [Powerpoint]. Workshop on Labour Force Participation and Economic Growth, Wellington. 14 April 2005

Idler, E., & Benyamini, Y. (1997). Self Rated Health and Mortality: A Review of 27 Community Studies. *Journal of Health and Social Behavior*, 38 (March):21-37.

Individualized Care. (2007). Individualized Care Organizational Self Assessment Tool. Quality Partners of Rhode Island. 1-4.

Institute of Gerontology. (2010). Mary L. James, M.A. Retrieved 16 January 2010 from <http://www.iog.umich.edu/faculty/james.html>.

Interrai CA. (2010). interRAI – CA Contact Assessment. Retrieved 14 January 2010, from <http://www.interrai.org/section/view/?fnode=44> .

Interrai.org. (2008). Interrai Moves to Develop a Self-Reported Quality of Life Assessment System. Retrieved 5 October 2009, from www.interrai.org/news/view/?display=more&item_id=28.

Interrai.org. (2009). Mission and Vision. Retrieved 5 October 2009, from www.interrai.org/section/view/.

Interrai.org. (2010). InterRAI HC - Home Care. Retrieved 13 January 2010, from <http://www.interrai.org/section/view/?fnode=15>.

Interrai QoL Research. (2010). interRAI Quality of Life Research. Retrieved 21 February 2010, from <http://www.interrai-au.org/newsletters/NZ%20OZ%20newsletter%20issue%203.htm> .

James, Mary. Personal Communication. 12 January 2010.

Johncarter.co.nz. (2010). Speeches by John Carter MP. Retrieved 30 January 2010, from <http://www.johncarter.co.nz/speeches.htm> .

Kamphuis, M., Ottenkamp, J., Vliegman, HW., Vogels, T., Zwinderman, KH., Kamphuis, RP., Verloove-Vanhorick, SP. (2002). Health related quality of life and health status in adult survivors with previously operated complex congenital heart disease. *Heart*. 87(4): 356–362.

Kemper, P., Applebaum, R., & Harrigan, M. (1987). Community care demonstrations: What have we learned? *Health Care Financing Review*, 8(4): 87-100.

Kind, Viki. (2009). Ageing in Place interview with Viki Kind of Kind Etics. Retrieved 7 December 2009, from <http://ageinplace.com/aging-in-place-interview-with-viki-kind-of-kind-etics/>

Koopman-Boyden, P., & Waldegrave, C. (2009). Enhancing Wellbeing in an Ageing Society – 65-84 year old New Zealanders in 2007. Population Studies Centre, University of Waikato.

Landi, F., Tua, E., Onder, G., Carrara, B., Sgadari, A., Rinaldi, C., Gambassi, G., Lattanzio, F., & Bernabei, R. (2000). Minimum Data Set for Home Care: A Valid Instrument to Assess Frail Older People Living in the Community. *Medical Care*, (38)12, 1184-1190.

Marczyk, G., DeMatteo, D., & Festinger, D. (2005). *Essentials of Research Design and Methodology*. Hoboken, New Jersey, United States.

Martin JO, Martin IR. Assessment of Community Dwelling Older People in New Zealand: A review of the tools [Final Report]. Retrieved 5th September 2009, from http://www.nzgg.org.nz/guidelines/0030/Final_Report_tools_review.pdf; 2003.

McGinnis, J-M., Williams-Russo, P., Knickman, J-R. (2002). The Case For More Active Policy Attention To Health Promotion. *Health Affairs*, (21)2, 78-93.

Meates, David. (2009). Minutes of the Canterbury District Health Board Meeting Held in the Board Room, Te Waipounamu House on Friday 13 February 2009 commencing at 9.00am. Retrieved 1 March 2010, from <http://www.cdhb.govt.nz/CorpBrd/HACMeetings/2009/03@Apr02/MINS%20-%20Board%20Public%20-%2013%20February%202009.pdf>.

Mercer.co.nz. (2010). Time to fix NZ's retirement savings system – Mercer launches white paper. Retrieved 3 March 2010, from <http://www.mercer.co.nz/referencecontent.htm?idContent=1353145>.

Merriam-Webster.com. (2010). Cognitive. Retrieved 7 March 2010, from <http://www.merriam-webster.com/dictionary/cognitive>

MDS-HC Form. (2001). Minimum Data Set Home Care (MDS-HC) New Zealand Full Assessment. interRAI Corporation.

Ministry of Health. (2002). Health of Older People Strategy. Retrieved 24 January 2010, from <http://www.moh.govt.nz/publications/hops>.

Ministry of Health. (2009). ASPIRE. Retrieved 6 December 2009, from <http://www.moh.govt.nz/moh.nsf/indexmh/aspire-factsheet>.

Ministry of Social Development. (2008). New Zealand Superannuation. Retrieved 25 January 2010, from <https://www.msd.govt.nz/about-msd-and-our-work/publications-resources/statistics/statistical-report/statistical-report-2008/superannuation-and-pensions/superannuation.html>.

Morris, J., Fries, B., Mehr, D., Hawes, C., Phillips, C., Mor, V., & Lipsitz, L. (1994). MDS Cognitive Performance Scale. *Journal of Gerontology*. 49(4), M174-M182.

Newstalkzb. (2009). Backing for rise in pension age. Retrieved 7 November 2009, from <http://www.newstalkzb.co.nz/newsdetail1.asp?storyID=165453>.

Nsrider.com. (2010). Henry David Thoreau Happiness. Retrieved 28 April 2010 from <http://www.nsrider.com/quotes/happiness.htm>.

NW London Stat Health Authority. (2010). Listen to what I'm Saying: Person Centred Care and the Single Assessment Process. Department of Health/North West London Strategic Health Authority. 1-4.

nzherald.co.nz. (2009). Pressure of Govt to raise super age. Retrieved 7 January from http://www.nzherald.co.nz/retirement/news/article.cfm?c_id=305&objectid=10576730&pnum=1.

NZiRA. (2002). NZiRA News. Retrieved 6 December 2009, from http://www.victoria.ac.nz/nzira/downloads/newsletters/nzira_news_0210.pdf.

NZ Treasury Department. (2009). Challenges and Choices: New Zealand's Long-Term Fiscal Statement. Retrieved 21 January 2010, from <http://www.treasury.govt.nz/publications/media-speeches/speeches/longterm>.

NZ Treasury Department. (2006). New Zealand's Long-Term Fiscal Position Superannuation Drivers of expenditure - Age of eligibility. Retrieved 25 January 2010, from <http://www.treasury.govt.nz/government/longterm/fiscalposition/2006/30.htm>.

Odds ratios. (2010). Summary statistics for dichotomous outcome data. Retrieved 13 March 2010, from <http://www.cochrane-net.org/openlearning/html/mod11-4.htm>

OECD. (1994). Care for Frail Elderly People: New Directions in Care. Organization for Economic Co-Operation and Development. Paris

OECD. (2007). Pensions at a Glance Public Policies Across OECD Countries. Retrieved 25 January 2010, from http://mpa.ub.uni-muenchen.de/16349/1/MPRA_paper_16349.pdf.

Office for Senior Citizens. (2001). Executive Summary. Retrieved 18 November 2009

<http://www.osc.govt.nz/positive-ageing-strategy/publication/executive-summary.html>.

Office for Senior Citizens. (2008). Forward Minister for Senior Citizens. Retrieved 21 December 2009, from <http://www.osc.govt.nz/positive-ageing-strategy/publication/ministers-foreward.html>.

Office for Senior Citizens. (2009). Part 2: Issues and Challenges for Ageing in Place. Retrieved 24 November 2009 from <http://www.osc.govt.nz/publications/briefing-incoming-minister/2005/part-2.html>.

Office for Senior Citizens. (2002A). New Zealand Positive Ageing Strategy. Retrieved 15 July 2009, from www.osc.govt.nz/positive-ageing-strategy/index.html.

Office for Senior Citizens. (2002B). Chapter 6 The Health of Older People. Retrieved 23 January 2010, from <http://www.osc.govt.nz/publications/briefing-incoming-minister/2002/chapter-6.html>.

POSM. (2006). Participant Outcomes and Status Measures (POSM) [Assessment]. University of Michigan: Centre for Information Management, Inc.: Draft C Form 1.0.3.

Quality of Life Project. (2010). Quality of Life '08 in 12 of New Zealand's Cities. Retrieved 13 February 2010, from <http://www.bigcities.govt.nz/index.htm>.

Rhode Island Department of Health. Office of Facilities Regulation. Retrieved 15 January 2010, from <http://www.health.ri.gov/nursinghomes/individualizedcarepilot/>.

Riley, T., Mollica, RL. (1996). The Arizona Long Term Care System. The Journal of Case Management, 5(2), 78-82.

Sieber, J., & Stanley, B. (1988) Ethical and Professional Dimensions of Socially Sensitive Research. American Psychologist, 43, 49-55.

Slevin, M., Plant, H., Lynch, D., Drinkwater, J. & Gregory, W. (1988). Who Should Measure Quality of Life, the Doctor or the Patient? *British Journal of Cancer*, 57 (1): 109-112.

Squidoo. (2010). Aging in Place. Retrieved 24 January 2010, from <http://www.squidoo.com/ageinplace>.

Stats.govt.nz. (2010). Home – Statistics New Zealand. Retrieved 2 January 2010, from <http://www.stats.govt.nz/>.

Statistics New Zealand. (2009). Moving age-sex pyramids. Retrieved 16 October 2009, from www.stats.govt.nz/reports/people/moving-age-sex-pyramids.aspx.

Stats.govt.nz. (2009). Estimated Resident Population of New Zealand. Retrieved 17 October 2009, from www.stats.govt.nz/methods_and_services/population_clock.aspx.

Statistics New Zealand. (08 December 2008). Growth of Families and Households Projected to exceed population growth. Retrieved 24 October 2009 from <http://www.stats.govt.nz/~media/statistics/browse%20for%20stats/nationalfamilyandhouseholdprojections/mr06-31projections/nationalfamilyandhouseholdprojections06-31projectionsmr.aspx>.

Statistics New Zealand. (2010). Population Ageing in New Zealand. Retrieved 16 January 2010, from <http://www.stats.govt.nz/reports/articles/pop-ageing-in-nz.aspx>.

Strahan, K., Swanson, I., Stamper, C., Jones, M., Elliott, S., & Mitchell, L. (2005). Holistic Care in the Community. NHS – Connecting for Health London. 1-4.

Stuff.co.nz. (2009). Retirement age discussion key. Retrieved 7 January 2009 from <http://www.stuff.co.nz/business/personal-finance/2409247/Retirement-age-discussion-key>.

The Press. (2009). Home help in spotlight. 15 August 2009.

United Nations. (2009). United Nations Statistics Division. Glossary. Retrieved from www.data.un.org/Glossary.aspx

Weissert, W., Lesnick, T., Musilner, M. & Foley, K. (1997). Cost Savings from Home and Community-Based Services : Arizona's Capitated Medicaid Long-Term Care Program. *Journal of Health Politics, Policy and Law*, 22(6), 1329–1357.

Weidenbohm, K., Parsons, M., Dixon, R., Keeling, S., Senior, H., Brandt, T. (2008). The interRAI evaluation: The Exploration of the interRAI training program implemented across five District Health Boards across New Zealand. Ministry of Health, New Zealand, 28.

Wood-Dauphinee, S. (1999). Assessing Quality of Life in Clinical Research: From Where Have We Come and Where Are We Going? *Journal of Clinical Epidemiology*, 52 (4), 355-363.

World Health Organization. (2009) What is “active ageing”? Retrieved from www.who.int/ageing/active_ageing/en/